Factors associated with improvement in the gross motor function outcomes of children with acquired brain injury in a paediatric intermediate care facility in the Western Cape, South Africa:

A descriptive study

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Declaration

I, Faiza Achmat, hereby declare that the work on which this thesis is based is my original work (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other university. I authorise the University to reproduce for the purpose of research either the whole or any portion of the contents in any manner whatsoever.

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Abstract

Aim: The study aimed to record the recovery patterns of gross motor function following acquired brain injury (ABI) in 17 participants, aged two to 14 years, receiving physiotherapy intervention at a paediatric intermediate care facility in the Western Cape, South Africa. Objectives of the study were to explore if factors such as age at injury, time since injury, intervention type, injury severity, gender, and the health- related quality of life of the child and caregiver were predictive of improvement of motor function and participation.

Methods: A quantitative, longitudinal, prospective cohort design with repeated measures was employed. The children received physiotherapy either intensively or intermittently within eight months post brain insult.

The Gross Motor Function Classification System (GMFCS) was used to classify the children according to their functional abilities. The Gross Motor Function Measure 88 (GMFM88) was used to assess changes in the child's gross motor function. The Paediatric Evaluation of Disability Inventory (PEDI) evaluated functional performance in daily life activities (participation). The EQ-5D-Y proxy version and the Caregiver Strain Index (CSI) evaluated the health-related quality of life of the children and caregivers respectively. Assessments were performed at Baseline, Week 3, 7, 9 and 13 after admission to the study.

Analysis: Descriptive statistics were used to describe the demographic data of the participants. Non-parametric analysis was performed to determine the time points at which the greatest improvement occurred because the sample was relatively small to support an adequately powered randomized intermittent trial. The GMFM88 was the primary outcome measure and the changes in score over the 13-week study period were plotted graphically in an attempt to identify patterns of improvement. The change in score from Baseline to Week 3 was also used as the dependent variable in investigating the determinants of short term improvement between the five measurement time points. Scatterplots and Spearman's rho were used to investigate the relationship between changes in GMFM88 score from Baseline to Week 3 and the age of the child at injury, time from injury and Baseline GMFM88 score. The Kruskal Wallis ANOVA for ordinal data was used to establish whether there were differences in all the outcome measures at the different time points: between Baseline and

Week 3, between Week 3 and Week 7 and between Week 7 and Week 9 and, if significant, a post-hoc Sign test was done to see where the differences lay. The effect size was calculated by dividing the z value by the square root of the total number of observations at both time points. Simple regression analysis was used to determine the variance in Week 9 GMFM88% score accounted for by the Baseline score.

Results: Seventeen participants met the inclusion criteria and were recruited. There were more boys (n=14) than girls (n=3) admitted with brain injury and the majority of the total sample (n=14) were drawn from families with minimal financial resources. Although no differences were found between the two intervention groups, the greatest improvement in GMFM88 scores was observed within the first three weeks of intervention, regardless of the time since injury. Three patterns of recovery were identified through plotting the GMFM88 scores: Group A, included participants with a high baseline score who showed sustained but small improvement until reaching the ceiling score; Group B, participants who started with lower scores and then improved considerably; and Group C, participants who started with low scores and showed slower and smaller improvement. Most participants (n=13) returned to near normal motor function after Week 9 (over 90% on the GMFM). Four participants did not show the same improvement: The Week 9 GMFM88 score was less than 60% in one participant and less than 30% for the other three. In this study, participants who showed the greatest improvement were those children on GMFCS levels three and four. The Baseline GMFM88 scores were significantly correlated with other time points (rho=0.886 at Week 9 and 0.748 at Week 13), but not with the change in scores. The effect size of the change in GMFM88 scores from one time point to the other were all measured as medium (effect size of 0.5 but less than 1.3) and the largest effect size was seen between Baseline and Week 7 (effect size=.660). Change in score from Baseline to Week 3 was not predicted by gender, cause of injury or method of intervention delivered (intensive or intermittent). The Baseline motor score accounted for 86% of the variance of the Week 9 GMFM88% score and each point in the baseline score increased the Week 9 score by .94.

The PEDI Mobility Score demonstrated a similar pattern of improvement to the GMFM88, but the pattern in progression of the PEDI Self-care domain was less clear. The EQ-5D-Y Proxies indicated that at Week 13, at least five children still had problems in one or more of the dimensions, with the greatest number (n=-8) having problems with the Usual Activities

and Worried, Sad, or Unhappy domains. The older (above age nine years), higher functioning children made less gains in their functional abilities.

The greatest cumulative cause of strain reported by the thirteen respondents, was a change in the former self of the child, followed closely by financial strain and work adjustments. The caregivers of the children in Group C, the most disabled group, experienced double the strain at Week 13 than caregivers of children with mild and moderate brain injury. Although not correlated at Baseline, the CSI was negatively correlated with the proxy EQ-5D-Y reported visual analogue general health scale at Week 13 (n=10, rho=-724, p=.018) .655, p=.021).

Conclusions: Although, most participants in the study regained physical functioning, approximately 25% admitted for rehabilitation with ABI might have significant residual motor damage and require on-going rehabilitative support. Although there were no other factors identified which predicted the outcome, these children could be identified based on poor GMFM88 scores on admission to rehabilitation. The EQ-5D-Y indicated that at Week 13, eight of the 12 proxies reported that participants had problems with anxiety and depression. Rehabilitation might therefore need to include a greater emphasis on self-care and mental health of the child, even when motor control has been established. Planning of long-term support should start early to maximise recovery and reduce the stress on caregivers. The study findings cannot be generalised due to the small sample size, but the results should alert therapists at the Facility to the possible long-term outcomes of children admitted with ABI. The study findings can assist with the formulation of patient specific and family centred rehabilitation care plans for children admitted with ABI at the Facility.

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Glossary of terms

Term	Abbreviation	Definition
Acquired Brain injury	ABI	Acquired brain injury is defined as damage to the brain due to a traumatic or non-traumatic cause that occurred after birth and is not related to a congenital neurodevelopmental disorder or hereditary disorder [1, 2].
Traumatic brain injury	TBI	It is defined as "*an alteration in brain function, or other evidence of brain pathology, caused by an external force"* [3] p. 1637.
Non- traumatic brain injury	NTBI	Injury to the brain due to a non- physical internal cause such as infection, haemorrhages, ischaemia and brain tumours [4].
Standard Care		Physiotherapy is provided as standard once to two times weekly at the research facility.
Caregiver		The person who is primarily responsible for looking after the child daily.
Rehabilitation		Rehabilitation refers to interventions provided to facilitate optimal recovery and restoration of function after an illness injury or disease [5].
Intermediate Care	IC	Intermediate care refers to transitional or subacute care provided on an inpatient basis to facilitate the recovery of skills and regain abilities in daily living for discharge home or an alternative living environment [6].
Baseline		Measurements taken at the commencement of the study are referred to Week one or Baseline measures.
Participation		Participation refers to a person's level of involvement in everyday life activities within their lived environment such as in the school, home, and community [7].
Gross Motor Function Measure	GMFM	Outcome measure used to measure change in motor function over time.
Gross Motor Function Classification Measure	GMFCS	The GMFCS is the most commonly used standard to classify children with cerebral palsy, according to the child's abilities and limitations in gross motor function in everyday life [8].
Paediatric Evaluation of Disability Inventory	PEDI	The Paediatric Evaluation of Disability Inventory (PEDI) assesses changes in the functional abilities and performance in daily activities of children aged six months to seven and a half years [9].
Caregiver Strain Index	CSI	The Caregiver Strain Index (CSI) is a 13 item measurement tool used to screen and evaluate parenting issues that might lead to parent and child behavioural problems [10].

Chapter 1. Introduction

1.1 Introduction

Acquired brain injury (ABI) is defined as damage to the brain due to a traumatic or non-traumatic cause that occurred after a period of normal childhood development has taken place [11-13]. It is unfortunately more common in low to middle countries [14], which, including these injuries, account for more than 90% of the years lost due to disability in children younger than 15 years. Furthermore, the injury mortality rate amongst children younger than 15 years in South Africa is 22.2 per 100,000, of which 6.8 per 100,000 deaths are due to a traffic related incident [15, 16]. For those that survive, ABI can lead to ongoing severe disability and disruption of the patient and their family's life [17, 18].

According to several studies, a traumatic brain injury (TBI) is the most prevalent form of ABI in children [19-24]. A large proportion of children hospitalised in the Western Cape Province of South Africa are due to severe traumatic brain injury (80% of those injured) [25]. Falls and road traffic related injuries are one of the leading causes of TBI requiring hospitalisation [15]. TBI in children is clearly of major concern, in terms of prevalence and impact.

Comprehensive rehabilitation may play an important role in the recovery of motor function, post brain injury [26, 27]. Furthermore, the acquisition of skill and reintegration in different areas of the physically disabled child's life are reported to be affected by the availability of rehabilitation services [28]. According to Anderson et al. (2011), to be effective, paediatric rehabilitation should be tailored to meet the needs of children, because children differ developmentally and physically from adults and are thought to follow a different recovery trajectory compared to adults post brain injury [29]. The functional recovery rate in children are slower in comparison to adults, who, during the first three to six months post injury, show a rapid rate of recovery and then slows down to small gains up until two years [29].

There are two causes of ABI, traumatic or non- traumatic incidents [18]. In the event of a very young child sustaining a brain injury due to a non-traumatic cause, (e.g. an infection or stroke), the recovery rate is expected to be slower compared to the older child with a brain injury due to a traumatic cause [29]. This might be, because of the suspected increased vulnerability of sustaining an injury at a very young age, as a result of the child's developing brain [30]. Poor functional recovery might result, because of the immaturity of the brain and

the increased risk to reorganise itself [31, 32]. Whereas, older children are expected to have a better chance of recovery as developmentally they would normally have acquired their motor skill milestones [33]. Rehabilitation in the latter, is then geared towards relearning and learning of skills [34]. Therefore, Forsyth et al. (2012) recommend that the age, developmental stage of the child, and environmental factors are taken into account in rehabilitation planning in order to facilitate the child's optimal recovery [2].

To assist with the restoration of motor function post a brain injury, physiotherapy is generally provided as part of the comprehensive multidisciplinary rehabilitation input given to children [35]. A variety of treatment strategies are employed by physiotherapists, such as, constraint induced therapy, neurodevelopmental therapy (NDT), balance and strength training to obtain the objective of improved motor outcomes post brain injury [36, 37]. However, there is limited evidence to support the effectiveness of different methods of physiotherapy delivery on functional performance post paediatric brain injury in terms therapy dosage [38-40]. As Parks et al. (2016) stated regarding Cerebral Palsy (CP) "*few studies have provided guidelines for therapy intensity*." (p1988), especially in relation to TBI. The Treatment Frequency Guidelines (TFG) and Treatment Frequency and Duration Guidelines (TFDG) were developed and piloted for children with CP, and four levels of intensity of service delivery were identified [41], ranging from intensive (3 to 11 times a week) to consultative (episodic or as needed) [42]. No studies were found that were specific to the duration and intensity of physiotherapy for children with TBI.

There is some evidence supporting the use of periods of intensive treatment in children with CP. A review of studies on neurodevelopmental treatment intensity indicated that intensive neurodevelopmental therapy in children with CP led to improved motor outcomes (1.32; 95% confidence intervals (CIs) l: 0.55–2.10), though the effect size was moderate [43]. In contrast, Christiansen et al. (2008) concluded that the organisation of the treatment programme in their study had no impact on the outcome [44]. They evaluated the impact of continued versus an intermittent physiotherapy treatment regime on the Gross Motor Function Measure (GMFM66) scores of 25 children ($median_{age}$= 3.0 years) with CP. Physiotherapy intervention was given over a 30-week period, either intermittently four times a week for four weeks alternating with a six-week treatment rest period, or continuous once or twice a week in their study [44]. In South Africa, a report on children

with CP living in rural South African communities, suggested that a five day programme of intensive neurodevelopmental therapy was effective in achieving improved gross motor skills and participation of these children [45]. However, there is a paucity of evidence on the effectiveness of different forms of service delivery for rehabilitation interventions in children with an ABI, as most of the available data are either related to adults with brain injury or children with CP [46].

Nevertheless, rehabilitation provision after an ABI is recommended [28, 47, 48], but paediatric rehabilitation services in the Western Cape are misaligned to the high incidence of TBI in the province [49, 50]. Also paediatric rehabilitation service tend to be concentrated at tertiary level hospitals that are far from the communities they serve, further compounding accessibility due to traveling associated costs [51, 52]. Adherence to hospital appointments might be negatively affected, in context of 55% of the SA child population living in a household with an income below the breadline [53-55]. Children might then miss rehabilitation and health care support needed to manage the consequences of a disability [56, 57].

1.2 Background to the study

An objective of the paediatric intermediate care facility where the researcher is employed, is improving access to health and rehabilitative care for children with chronic and life-threatening illnesses coming predominantly from resource poor communities [58]. The limited availability of paediatric rehabilitation services in the Western Cape motivated the implementation of a three-year pilot intermediate care rehabilitation project at the Facility in August 2013. An objective of the project was to facilitate the children's functional restoration in order to successfully reintegrate the children back home, within their communities and school environments [59]. Specific questions related to the efficacy of the rehabilitation service delivery emerged during the project implementation. The research study was then undertaken to answer the emerging questions related to rehabilitation service provision at the Facility. A description of the research setting follows based on information gathered from the Facility's website.

The Facility is one of two paediatric intermediate care facilities in the Cape Metro. Intermediate care has been provided to children from birth to 17½ years old at the faith based facility since 1935 [58]. During admission, the children continue with their education

at a Western Cape Education Department school situated on the premises. The school offers special needs education via an adapted mainstream and special education curricula. The Facility offers post-acute, restorative, palliative, rehabilitative, and respite care. It has a bed capacity of 140. Services include 24-hour nursing, and therapeutic, spiritual, and psychosocial care. Patients must be medically stable to qualify for admission, meaning their condition must be stable enough to not require daily monitoring from a medical doctor. The Facility uses the Landrum rehabilitation outcome levels (Appendix 1) as a reference guide to determine medical stability as outlined in the Western Cape Government Department of Health 2030 document [58, 60].

The therapeutic service at the Facility expanded in August 2013 when the pilot rehabilitation project commenced. The Facility developed an electronic database to assist with the monitoring, evaluation and reporting of the pilot rehabilitation project to funders. According to records from the Facility electronic database, the annual intake of children requiring rehabilitation changed from about five before August 2013 to 103 between August 2013 to December 2014 [61]. Reports to funders at the end of 2014 indicated that about 50 of 103 patients admitted for rehabilitation since the start of the project had an ABI [59]. The most prevalent cause of ABI, 36 out of 50 children admitted, was TBI due to incidents such as pedestrian vehicle accidents and blunt trauma incident. An ABI due to a non-traumatic (NTBI) incident such as ischaemia, cerebral tumour, TB meningitis, cerebral anoxia or encephalitis accounted for the remaining 14 admissions. These report findings were supported by the results of similar studies indicating that TBI tend to be the most prevalent form of an ABI [62]. The project reports also implied that NTBI was more prevalent in admitted patients aged six months to five years, whereas patients aged six to 14 years appeared to have acquired their brain injury mostly due to a TBI. In the school aged group, TBI injury also appeared to be more prevalent amongst the boys compared to the girls. These children required rehabilitation and support from the Facility to help them recover and cope with the consequences of their brain insult.

Most of these children (about 36) received input once or twice weekly over a six-month period whilst the remaining 14 received two weeks of daily therapy. Therapy was delivered via two streams of multidisciplinary rehabilitation to these patients either on an in-or outpatient basis. In the one programme, 14 children were admitted for intensive therapy.

With the intensive regime, therapy was provided daily for two weeks, followed by discharge home. After that, home based therapy was provided on a weekly basis for an initial three-month period and then monthly, up to a period of 18 months post discharge. Home based therapy was provided via rehabilitation care workers (RCW) employed at the Facility. The therapists conducted a follow up review at three, six, 12 and 18 months post-discharge to assess if a patient required or would benefit from a readmission and a further one-week period of intensive therapy. In the other rehabilitation regime offered, therapy was provided to 36 children once or twice a week over six months, followed by discharge home.

A focus area of the project was caregiver involvement in the rehabilitation process, because the extent of at which a caregiver is involved is viewed as a moderator in the recovery of children with brain injury [17,18, 63]. Caregivers were either a parent or legal guardian of the child. A request was extended to caregivers to attend at least three caregiver-training sessions during their child's length of stay. However, the involvement of caregivers did not occur as envisaged. Instead, caregiver's attendance at training sessions varied from 1) daily attendance in therapy over a two-week period; to 2) once to three times during the child's stay; and to 3) no involvement. This variation occurred despite the availability of onsite accommodation to caregivers should they wish to stay in at the Facility.

The differences in caregiver involvement, the two streams of service delivery and the infancy of the Facility rehabilitation service, gave rise to questions regarding the effectiveness of the rehabilitation service provided to children with ABI at the Facility and how to generate research evidence to support this service. The research questions described in section 1.3 were thus formulated to assist the Facility in reaching its objective of providing a family centred physiotherapy service to children with ABI and their caregivers.

1.3 Research questions

The outcome of physiotherapy treatment is likely to be different to that of published literature as the challenges of providing optimal care within the local context are considerable. Caregiver and rehabilitation resources that might be available in high income countries are considerably constrained and a better understanding of the local context is required to plan for an optimal rehabilitation support programme for each child. In this way each child could receive the most effective form of intervention related to their own circumstances. It was thus necessary to understand the resources that were available and

the form of physiotherapy intervention that was associated with improvement for diverse groups of children with ABI. To inform the choice of intervention support, several questions needed to be answered. What support structures were in place for the child and his or her caregiver? What are the factors that predicted functional improvement? Would rehabilitation intervention result in an improvement in all children, despite the level of initial severity? When does the most improvement take place? Does the time since insult make a difference to the amount of improvement seen? Was an intensive period of daily physiotherapy programme, given over two weeks, associated with an improved function and health related quality of life in children with an ABI compared to less intensive therapy over a longer period? Would the amount of improvement be related to the age of the child? Is the time from injury related to the outcome? The answers to these questions would then help to guide the effective provision of future physiotherapy interventions to this cohort at the Facility, and possibly at other facilities that provide physiotherapy at an intermediate care level to children in the Western Cape.

1.4 Aims and objectives of study

This descriptive research study aimed to chart the progress of motor recovery after admission to the Facility to determine the factors impacting on the gross motor outcomes of children aged two to 14 years with an ABI receiving physiotherapy within eight months post brain insult.

The specific objectives were to:

1. Describe the home situation of each child to gauge the amount of support that could be available to the child and caregiver.
2. Describe and chart the change from admission to the programme to nine weeks post admission in
    a. Motor function as measured using the Gross Motor Function Measure (GMFM88) [64],
    b. Participation measured by the Paediatric Evaluation of Disability Inventory (PEDI) [39],
    c. Health Related Quality of life (HRQOL) using the EQ-5D-Y [65]
    d. The burden of care on the caregiver monitored by the Caregiver Strain Index [66].

3. To establish at what time points the greatest improvement was observed: between Baseline and Week 3, between Week 3 and Week 7, and between Week 7 and Week 9.
4. To determine which factors were associated with improvement in the GMFM88 from Baseline to Week 3. These factors included the age of the child, the time since injury, injury severity and the Baseline GMFM88 score.

1.5 Justification and significance

Studies evaluating motor outcomes in children post ABI are limited [64] and as mentioned above under 1.1, there is no clarity as to which form of delivery is preferable. As both intermittent and intensive programmes were on offer at the Facility, it would be useful to determine if either was predictive of improvement in motor function. Unfortunately, the number of participants in the current study were too small and the condition of the children too heterogeneous to support an adequately powered randomized intermittent trial, but the current research study might add to the pool of knowledge on the effectiveness of physiotherapy on the motor outcomes for children with ABI at the Facility. The results of the study could help to set up best practice guidelines on the provision of rehabilitation to these children. Finally, the results could inform the development of standard packages of care which could assist with effective monitoring and evaluation of the Facility's rehabilitation service delivery.

Chapter 2. Literature review

2.1 Introduction

The literature review describes the nature of acquired brain injury (ABI) in children, specifically the causes, types, and the epidemiology. The process of recovery from ABI with reference to neural plasticity and the role of rehabilitation services are considered. The health care service delivery model in the Western Cape (comparing current services with policy recommendations), and the role of the caregivers as partners in rehabilitation are explored. In addition, the relevance of outcomes-based rehabilitation, the use of outcome measures and factors impacting on recovery will be discussed.

The World Health Organisation (WHO) International Classification of Functioning and Health Disability (ICF), the UN Convention on the rights of children with disabilities and the South African white paper on the rights of persons with disability are employed as a reference frameworks. Key words searched were acquired brain injury, traumatic brain injury, paediatrics, child, caregiver strain, burden of care, South Africa, physiotherapy, rehabilitation, and motor outcomes. Databases searched were PubMed, Medline, CINAHL, EBCSCO, Open UCT, ClinicalKey and Google scholar.

2.2 Framework of the review: The International Classification of Function and Disability (ICF)

One of the challenges faced by the research Facility is the lack of guidelines in rehabilitation service provision to children with ABI. Rehabilitation is provided at an intermediate care level via a multidisciplinary team as part of the continuum of care with the aim to ultimately reintegrate these children back home and in society (more about this in section 1.2). However, no gold standard guides current physiotherapy service provision.

The adoption of the International Classification of Functioning Disability and Health (ICF) could assist the Facility in reaching its goal to discharge patients home successfully (see figure 2-1). The ICF provides a common language across the different levels of care and across disciplines. The ICF was developed by the World Health Organization (WHO) and ratified by the WHO Assembly in May 2001 [52,67, 68]. Health related conditions are

explained in correlation to the contextual factors such as environmental and personal factors [69, 70].

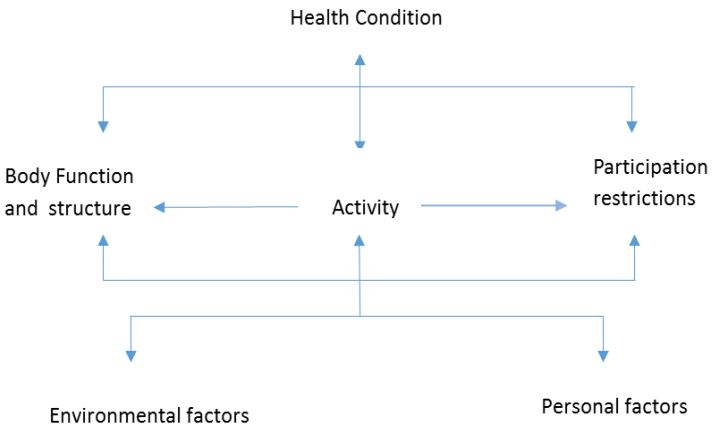


Figure 2-1: Illustration of the ICF model [71]

The ICF is used in rehabilitation to describe the child's condition, assist with treatment planning, assist with treatment goal setting and to implement treatment accordingly [72]. The ICF could thus be used to guide the physiotherapist to provide intervention in a holistic manner by relating motor ability to participation within relevant environmental contexts of the child's lived experiences. Therapy goal setting might for example thus aim to enhance participation in everyday living situations whether it is in the classroom, home or community. Intervention could also include adaptations to the environment or the provision of alternative devices to enhance mobility [73]. However, a paucity of evidence exists to support the impact and efficacy of physiotherapy in children with ABI.

2.3 Acquired Brain Injury (ABI)

Children with ABI formed part of the child population accessing rehabilitation at the Facility during a 15-month period (September 2013 to December 2014), this cohort accounted for about 50 of an intake of 103 children admitted to the research facility after a three-year pilot rehabilitation project started at the Facility in August 2013. Physiotherapy was provided to these children to facilitate their functional recovery. However, the diversity in the clinical presentations of these children with ABI posed challenges to the clinical team.

The treatment of children with ABI was novel, therefore an understanding of what an ABI is, the recovery of motor function post ABI and factors that might influence outcomes of motor function and participation were thus required. The therapy team required guidance and information to reach their aim in delivering an optimal service to these children. An exploration of what ABI is, the possible implications for the child, caregiver, and family in context of their socioeconomic circumstances and current rehabilitation service provision are thus explored.

2.3.1 Definitions and subtypes

Acquired brain injury is defined as damage to the brain due to a traumatic or non-traumatic cause that occurred after birth and is not related to a congenital neurodevelopmental disorder or hereditary disorder [1, 2, 74]. Importantly, when the injury occurs before birth, during birth or immediately after birth, the child is referred to as having CP [75-77] and not ABI. ABI may be classified according to levels of severity, ranging from mild to severe [78, 79]. The Glasgow Coma Scale (GCS) is the gold standard measurement used to determine brain injury severity [80] and a score is usually determined on admission to hospital following an injury. The GCS rates injury severity range on a measurement from zero to fifteen [81]. A score below eight indicates a severe injury; a score of nine to twelve indicate a moderate injury; and a score of 13 to 15 a mild injury [82-85]. In addition to motor problems, children might also experience problems in cognitive, emotional and behavioural function post injury affecting recovery and participation [1, 86]. Advancements in acute medical and emergency care positively impact the possibility of survival post brain injury in children [87], but consequent morbidity might occur. Rehabilitation is therefore recommended, to address the consequences of the injury to possibly reduce morbidity and to facilitate maximum quality of life [88], in the short and possibly long term as the child develops and grow [89, 90].

2.3.2 Two main types of ABI reported; TBI and non-TBI.

2.3.2.1 Traumatic brain injury

The most common form of an ABI is traumatic brain injury (TBI) [2]. The definition of TBI according to Menon et al. (2010) is "*an alteration in brain function, or other evidence of brain pathology, caused by an external force"* [3] p. 1637. Brain damage due to TBI can be

diffuse (widespread) or focal (localised) and may further be classified as primary or secondary [91-93]. A TBI is classified as primary if the injury is directly related to the impact or secondary when it is due to further damage that might occur [92].

2.3.2.2 Non-Traumatic Brain injury

Non-traumatic brain injury (NTBI) is injury due to a non- physical internal cause [4]. The causes of NTBI is furthermore described as ischemic events, infections, brain tumours, and haemorrhage [94, 95]. Ischaemic stroke is one of the most prevalent forms of ABI in children and morbidity after a stroke is high requiring long term care [94]. Problems in motor functioning lead to activity limitation in children post ABI, though the extent of the limitation varies with injury severity [96]. In South Africa, Ndondo et al. (2011) reported that stroke during childhood is caused by inflammation or infection, such as bacterial meningitis, tuberculosis meningitis and HIV [94].

2.3.2.3 Clinical Presentation/Functional problems in ABI

Although research indicates that the prognosis of motor recovery is better compared to recovery of cognitive function, long term problems in balance, strength, and speed are often experienced [97, 98]. Fall out in these areas might affect the quality of motor function [99]. Furthermore the prognosis for independent ambulation post severe injury is poorer compared to mild and moderate injury [100]. Neurological fallout in motor function, cognition, and emotion might have long-term effects on the individual's ability to participate in activities of daily living, thus contributing to the economic burden of a society.

Emerging evidence is challenging previously held views which maintained that the young brain's ability to recover after sustaining a brain injury is better than adults [101]. Unfolding research reports that the young brain is particularly vulnerable, due to the immature brain still completing its development [83]. Injury might then interrupt the normal development of the immature brain [102-104]. Prognosis for recovery post stroke in the very young child (three years and below) is expected to be worse than in older children of school going age due to the age and developmental stage of the very young child at the time of injury [105, 106]. Multi-disciplinary rehabilitation is thus advocated to counter the consequences post stroke [107].

2.3.3 Outcome measures

Therapists are encouraged to use validated and reliable outcome measures to inform and evaluate the treatment approaches they employ and to ensure that the goals achieved are aligned to the child's needs. There are many outcome measures for use in children and in choosing suitable measures, it is important to align the measures with the different components of the ICF. A brief on some of the common measurements used to evaluate gross motor function and participation in children with ABI is given.

2.3.4 Activity limitations and participation restrictions

There are many outcome measures to evaluate the different factors that might affect the gross motor recovery post ABI. The measurements should be validated and reliable to measure the change in the different factors under exploration related to motor outcome in children with ABI so that goals achieved are aligned to the child's needs.

2.3.4.1 The WeeFim (Paediatric functional independence measure)

The WeeFim is the paediatric derivative of the Functional Independence Measure [39]. The WeeFim is one of the standardised outcome measures commonly used to assess independence in physical function in children with brain injury. The outcome measure was developed to evaluate the functional performance of children aged 6 months to 7 years [108] and can be used in children up until age 18 years [275]. The test has three domains consisting of 18 sub items each. The domains are self-care, mobility and cognition [109]. The child's independence is scored on a graduating scale from one (total dependence) to seven (complete independence) per item test. Validity correlation coefficient of 0.88 and interrater reliability of 0.90 to 0.99 in children with ABI are established. Change over time can be detected with this instrument [110]. Administration time is 20 to 30 minutes and accreditation is a prerequisite [111]. Like the GMFM88 the WeeFim is suitable for use in the acute and post- acute paediatric rehabilitation setting. Comparably though, the use of the WeeFim is more restrictive due to cost and copyright issues [112].

2.3.4.2 The Peabody Developmental Motor Scales-2 (PDMS-2).

The Peabody developmental motor scales determine the child's motor developmental level in early childhood compared to motor age-equivalent skills. The measurement is suitable for assessing children aged five and younger [113]. It consists of six subsets examining the gross

motor abilities of the young child. Inter-rater reliability of .97 and test-retest reliability of 0.95 to 0.99 was reported by Van Hartingsveldt et al. (2005) [114]. The inter-rater reliability was adequate. The PDMS-2 can be used across disciplines. Time to administer is 45 to 60 min [115].

2.3.4.3 The Pediatric Evaluation of Disability Inventory (PEDI)

The Paediatric Evaluation of Disability Inventory (PEDI) assesses changes in the functional abilities and performance in daily activities of children aged six months to seven and a half years [116]. It is closely aligned to the ICF, because it assesses function in relation to the environment [117. The PEDI can be used in older children if their functional skills are below those of a seven-and-a-half-year-old child that is developing typically. The PEDI is conducted using a structured interview with the caregiver who knows the child well [116]. The caregivers give an indication of the child functional capability and performance. For improved reliability interviews should be conducted by the same interviewer to the same respondent [33].

The instrument is divided into a functional skill, caregiver assist and modified scaled-sections [118]. The functional skills section consists of 197 items consisting of three domains: Self-care (73 items), Mobility (59) and Social function (65) [119]. The Self-care and Mobility subdomain scales measure adaptive and physical ability in daily life function respectively. Whereas the Social subdomain evaluates competence in social interaction. Capability is scored as one (1) and inability is scored as zero (0) for the functional skill items. The Caregiver Assist Modified scaled sections measures the child's performance. Each has 20 score items respectively. The Caregiver scaled items are rated on a scale of 0 (total assistance) to 5 (no assistance required). The Modified scaled items are rated on a four-point ordinal according to the amount of adaptations required in the environment and assistive devices required. The items are scored as N (none), C (child-oriented modification), R (rehabilitation equipment or assistive devices required), E (extensive modifications required) [116]. All the scores are presented on a scale of 0 (worst) to 100 (best) for skill and independence. A high internal reliability of 0.98, inter-rater and test retest reliability above 0.90 were found [116, 120]. Recommendation is for a trained administrator to conduct the measurement to ensure correct scoring. The PEDI takes 45 to 60 minutes to administer. It has widespread use in a variety conditions and settings such as hospitals; schools,

preschools, and clinics. Reliability was established in acquired brain injury and it was found to be a valid measure of paediatric function [121, 33]. An objective of the study is to evaluate change in the motor and self-care abilities children with brain injury plus the care demands on the caregiver. As a result, the self-care and mobility items of the functional skills section and caregiver assist sections were of relevance to the study.

2.3.5 Motor functioning – activity limitation

As the focus of this study is the impact of the factors discussed on motor function, the primary outcome measure was to monitor this function.

2.3.5.1 The Gross Motor Function Classification Scale

The GMFCS is the most commonly used standard to classify children with cerebral palsy, according to the child's abilities and limitations in gross motor function in everyday life. The GMFCS was originally developed in 1997 by Palisano et al. (2008) to describe the gross motor function of children with CP aged 12 years or younger [8, 122-124]. The child's ability to perform meaningful motor tasks in everyday life situations classify the child into five levels [125]. Motor abilities are categorised into the levels according to observed differences in the child's ability to perform self-initiated sitting, walking and transfers. Level one represents the least physically involved and level five the most disabled child. As the child's age is a determinant for motor abilities, age bands are incorporated in the classification system. Age bands less than two years; two to four years; four to six years and six to 12 years are used in determining GMFCS levels [126]. Growth Motor curves provide guidelines to clinicians regarding the potential for change within each GMFCS level [126]. The change is comparable to children with cerebral palsy in the same age category and GMFCS level. Person and family centered intervention are enhanced using the GMFCS. The GMFCS is used in teaching, clinical practice and research [8].

The Gross Motor Function Classification Scale (GMFCS) has an inter-rater reliability of 55% and 75% for children aged 12 and younger [121].

GMFCS Classification Levels are:

- GMFCS Level I – walks without limitations.
- GMFCS Level II – walks with limitations. Limitations include walking long distances and balancing, but not as able as Level I to run or jump; may require use of mobility

devices when first learning to walk, usually prior to age 4; and may rely on wheeled mobility equipment when outside of home for traveling long distances.

- GMFCS Level III – walks with adaptive equipment assistance. Requires hand-held mobility assistance to walk indoors, while utilizing wheeled mobility outdoors, in the community and at school; can sit on own or with limited external support; and has some independence in standing transfers.
- GMFCS Level IV – self-mobility with use of powered mobility assistance. Usually supported when sitting; self-mobility is limited; and likely to be transported in manual wheelchair or powered mobility.
- GMFCS Level V – severe head and trunk control limitations. Requires extensive use of assisted technology and physical assistance; and transported in a manual wheelchair, unless self-mobility can be achieved by learning to operate a powered wheelchair.

2.3.5.2 The Gross Motor Function Measure

The GMFM88 was originally developed for use in children with cerebral palsy aged five months to 16 years to measure change in motor function over time. It has an internal reliability of 0.99 and validity of r =0.82 [127].The GMFM has two versions, the GMFM88 and the GMFM66. Both versions are valid and sensitive tools to assess change in motor function in paediatric patients with traumatic brain injury [108, 128]. The GMFM88 and GMFM66 both has a high intra tester reliability of 0.99 [117]. The GMFM66 varies from the GMFM88, because the measurement scores can be computed using a computerised scoring system called the Gross Motor Ability Estimator (GMAE), which is standardised for children with Cerebral Palsy. Scores of the child's motor function are plotted on visual item maps normed for children with Cerebral Palsy. The GMAE is representative of specific motor development pattern of patients [218] with Cerebral Palsy and recommendation is therefore not for use in children with ABI [123]. The GMFM88 is administered as a standardised test in a controlled environment to assess the gross motor capability of the child. It consists of five dimensions: 1) lying and rolling; 2) sitting; 3) crawling and kneeling; 4) standing; 5) walking, running and jumping. Each dimension is totalled out of 100 and a 4–point scale is used to score each test item within a dimension [109]. Total score calculation is obtained by averaging the scores of the five areas. Administration time is 30 to 60 minutes

[130]. The amount of times and extent in which items are achieved can be calculated. The GMFM88 is time consuming and there is a risk of losing the child's attention. The measurement allows for the use of motivating tools such as toys to keep the children engaged and for encouragement. It is also easy to administer and free on line. Though, the GMFM66 have been reported to have ceiling effects for children older than five years [117].

2.3.5.3 Bruininks-Oseretsky test of motor proficiency, 2nd edition (BOT-2).

The Bruininks-Oseretsky test of motor proficiency, 2nd edition is standardised measure assessing the fine and gross motor function including motor proficiency and quality. It is applicable for use in ages four to 21 years. It consists of 8 subtests. There are two versions of the BOT-2, a shortened and complete version. The Pearson product moment correlation coefficients for inter-rater reliability for both versions were > 0.90 and test-retest reliability were > 0.80 in both tests. The complete version had an internal consistency of > 0.93 whilst the internal consistency of the Short Form was > 0.80 [131]. Administration is 15 to 20 minutes for the shortened version and 45 to 60 min for the complete test. The BOTI-2 is becoming more frequently used in the assessment of children with TBI [112, 114].

2.3.5.4 Bayley Scales of Infant and Toddler Development, 3rd Edition

The Bayley scales of infant and toddler development, 3rdEdition (Bayley-III) is recommended as a standardised measure to assess development in infants and toddlers aged one to 42 months post brain injury [132]. The measurement has five scales of which three evaluates language, cognitive and motor function and two assesses the socioemotional and adaptive behaviour of the child via a parent questionnaire. Administration time can vary from 30–90min [133]

2.4 Factors related to prognosis in ABI

2.4.1 Epidemiology

In South Africa, about 11.2 % of the child population live with disabilities [53], amounting to an estimated one million children in South Africa living with a disability [51]. Although it is assumed that ABI is a significant contributor to disability in children, there is little epidemiological information on ABI and TBI in South Africa [134, 135]. South African children are most at risk of a TBI as pedestrians [136]. Road traffic accidents are one of the leading causes of death and morbidity in children under 15 years in Cape Town [16].

Unfortunately the risk of sustaining TBI appears to be greater for children younger than 5 years and adolescents (boys more than girls) aged 15 to 19 years coming from impoverished backgrounds [14, 137-139].

Advances in trauma management has increased survival post TBI [140], but the corresponding morbidity is high [25]. A study conducted at Red Cross Children's Hospital, in Cape Town, in 2012, found that just over 38% and 15% of the children admitted with injuries between 1996 to 2006 were due to falls and road traffic injuries, respectively [15]. A follow up study at the same hospital by Isaac et al. (2015) analysed data of 4690 admissions due to road traffic accidents (RTA) during 1992, 2002 and 2012 [50]. Their study indicated that pedestrian vehicle accidents (PVA) accounted for 75% of these admissions and unrestrained passengers were second in line as a cause of injury. Further results were that injury severity was correlated to inpatient admission and that more boys than girls were admitted [50].

Injuries due to RTA (a 46% increase), falls and the prevalence of ischaemic stroke have risen in low to middle income countries, in spite of global prevention initiatives [141]. In South Africa, RTA are a major public hazard accounting for a permanent disability in 75000 people annually [142].The annual statistic for children acquiring a permanent disability due to accidents in South Africa is 3000 [143]. However, the epidemiology on paediatric TBI in South Africa remains unclear [145].

There are some outdated sources that report on the epidemiology of TBI in South Africa and Cape Town. In 1991, South Africa had an overall estimated traumatic brain injury rate of 316 per 100 000 [146]. Another study reported that 11.4% of children 13 years and younger admitted to Red Cross Children's Hospital trauma unit during 1984 and 1989 were due to a PVA's; whereas falls accounted for 43% of the trauma admissions [26]. Injury severity was worse in the PVA group requiring hospitalisation. A more recent study by Lalloo and Van As (2004) supported this finding, reporting the causes of head injuries in children are due to 41% falls, 19% traffic related (65% of these being due to PVA) and 13% blunt trauma [135]. Similar findings were reported in a follow-up study by Herbert et al. (2012) [15]. They explored the demographics, mechanisms, and severity of injuries of children admitted to Red Cross Children's Hospital according to the hospital's trauma surveillance registry for the period from January 1997 to December 2006; and reported falls as remaining the most frequent reported cause of injury (40%). Second in line were PVA's, accounting for about

70% of the road traffic related incidents admitted. The preschool aged child was reportedly more involved in a PVA and boys were more at risk to injury than girls.

In a recent editorial report published in the South African Journal of Medicine (2017), Van As and Dhai (2017) stated that inadequate supervision is a major contributor to the high injury rate causing morbidity in children [147]. For children younger than five, the risk to injury was greatest when unsupervised in or around the home, whilst the older school going child were more at risk when unsupervised en-route to and from school [147]. Moreover, they attributed the lack of caregiver supervision to parents having to work far away from home to provide an income for their family [148].

2.5 Recovery and rehabilitation

Effective rehabilitation program planning requires an understanding of how the brain responds to injury. Neural plasticity is an inherent process within the brain which enables the human brain to reorganise and modify itself throughout an individual's lifetime [29]. In the event of an injury or disease, the brain has the capacity to compensate for loss by reorganising itself and forming new neural connections and pathways [149]. Naoyuki Takeuchi [150] and Shin-Ichi Izumi explains this recovery process by describing how, synaptic connections become more fluid and modifiable, enabling the brain to develop new neuronal interconnections, in its attempt to restore, substitute and compensate for motor impairment [150].

ABI in children occurs at a time when rapid maturation takes place and periods of sensitivity occur [29], thereby increasing the vulnerability of the developing brain to injury [29]. Consequently, injury to the brain during this time might disrupt the normal process of neural plasticity in the healthy developing brain [151]. During this time, vulnerability to the consequences of brain injury is thought to be heightened, because development and skill acquisition is still ongoing. According to Forsyth et al. (2015), brain injury impacts on normal child development adversely and developmental delays can emerge over time. To address these consequences, rehabilitation is recommended to facilitate the achievement of functional recovery, because of its influence on neural plasticity [46]. A task-specific, stimuli rich intervention approach is recommended in order to reduce the formation of maladaptive connections so that recovery can be facilitated [150, 152].

Not with standing, the probability of walking achievement post injury, long term problems in movement quality and grading might be present post severe and moderate injury, which then require ongoing therapeutic attention [153]. Movement disorders such as alterations in muscle tone, muscle strength, posture, movement synergies, and coordination are common with motor cortex involvement [73]. Residual problems in motor, cognitive, perceptual and social function could negatively impact on the child's quality of life [151].

A reduction in quality of life might contribute to the burden experienced by caregivers in caring for their child [79], which could possibly unfold to other family members, the community and the economy at large [87]. Having measures in place to identify children at risk of long term motor fallout could mitigate such problems by putting rehabilitation support structures in place timeously [84].

In this light, rehabilitation provision should adopt a person centred approach addressing the injury in relation to social and environmental contexts [152]. Task specific strategies that are meaningful to the child, caregiver and family are advised in therapy to enhance participation [150]. Motivation can be facilitated by involving these role players in decision making within therapy and within the society [153]. Rehabilitation throughout the recovery process is thus viewed as key to facilitate participation and enable the affected individual to live an integrated life and a productive life as much as is possible within society [97].

2.6 Policy and rehabilitation

Children's right to be treated with dignity and respect are stipulated in the South African Constitution and the Children's Act that is aligned to the UN Convention on the Rights of the Child [53]. According to legislation, children have the right to life, survival, health, education participation and to thrive [154]. All children, including those with disability have the right to the opportunity to develop to their full potential, live a decent life in a dignified way and to participate within society to the best of their ability [155].

Despite the aforementioned, access to rehabilitation services for children with disabilities in South Africa remain inequitable and unrealised [160]. Moreover, limited access to health care and rehabilitation services, in combination with low socioeconomic circumstances, are linked to poor health outcomes [161]. Low socioeconomic environments might impact on

families ability to cope, which could possibly impact on the child's recovery [162]. Within the context of about 70% of South Africans living below the breadline [49], families might find it difficult to afford the health associated costs when caring for their child with a brain injury [163].

In higher income countries, the availability of rehabilitation programs at an intermediate care level, might aid patients with brain injuries (mild to severe) to achieve a better quality of life [47, 164]. Gray et al. (2012) looked at the access of paediatric patients, post traumatic injury, to rehabilitation services whilst admitted at a specialised neurosurgical centre [164]. A total of 146 cases were reviewed. Findings showed that 56% of the patients with severe TBI were assessed by a rehabilitation therapist, compared to 15% with moderate and 5% with mild injury. As a result, they proposed a multidisciplinary approach early during the intermediate phase irrespective of injury severity to achieve optimal recovery and improved quality of life of patients with mild to severe brain injury. In another retrospective study by Gray et al. (2000), they studied the impact of long-term multidisciplinary rehabilitation on the motor outcomes of a group of adults with an acquired brain injury [47]. This time their study cohort consisted of 207 patients with severe TBI and 138 patients with severe non-traumatic brain injury (NTBI). Results showed that beyond one year post injury, further functional recovery was possible in slow to recover patients with a severe acquired brain injury if ongoing long term therapy is provided [47].

In a study conducted by Groenewald et al. (2017), in the Western Cape province of South Africa, adults with stroke benefited from multidisciplinary rehabilitation input at an intermediate care [165]. London et al. (2015) advocates for IC facilities to be viewed as integral to the health care service delivery system in the Western Cape [6]. Their study looked at the role an adult intermediate care (IC) facility play in the continuum of care of patients in the Western Cape. Referrals for rehabilitation to the IC facility, coming predominantly from secondary level hospitals (about 25 out of 68 admitted) were evaluated. They found that the most common referrals made were among patients who experience stroke (35%). Patient and family satisfaction with services was high, describing the facility as a caring environment. However, paucity in patient referrals to community health care workers and follow up by community-based services were reported. Further

recommendations were the development of a comprehensive IC policy to guide the delivery of care packages at an intermediate care facility [6].

2.6.1 Overview: Rehabilitation services in the Western Cape

Intermediate care services forms part of primary health care [166] providing a continuum of health and rehabilitative care from tertiary to community care level in accordance with the vision of the Western Cape Department of Health (WCDOH) 2030 policy [167]. Additionally, the WCDOH promote the provision of services at a primary care level, bringing health and rehabilitative care closer to communities. However, there are only two paediatric intermediate care facilities in the Western Cape providing rehabilitation and health care to children coming from predominantly resource poor communities [168]. The paucity in paediatric rehabilitation services in the Western Cape might result in unmet needs of the child and their family as postulated in studies conducted in high income countries [97], though no concrete evidence exist to support the direct impact of rehabilitation on functional outcomes [46]. Despite the WCDOH's vision to decentralise health care, rehabilitation services at district and community level remain scarce [169]. Resources in community-based services particularly paediatric rehabilitation remain marginalised and no dedicated government paediatric rehabilitation facility exists at community level in the Western Cape.

A task team was established in 2015 to address the lack of rehabilitation service and identify ways to enhance the rehabilitation service capacity of community and primary level services [51]. The vison of this paper is embedded in the National Department of Health document, Framework and Strategy for Disability and Rehabilitation Services in South Africa 2015 – 2020 [170]. The 2015-2020 document advocates the decentralisation of rehabilitation services towards a primary health care approach. Rehabilitation is further viewed as a pillar of primary health care, providing a continuum of care to maximise the potential to live life to the fullest and to improve quality of life. Rehabilitation services should thus be equitable and accessible. To achieve this goal, clearly defined referral pathways need to be established to ensure that the person requiring rehabilitation is supported as they need it. Intermediate care forms part of the community-based service arm of the primary health care system in the Western Cape. Rehabilitation services at this level bridges the gap between tertiary level care and community based care [6], thus adding to the continuum of

care proposed in the 2015-2020 national DOH document. Moreover, significant functional gains were reported in patients with traumatic brain injury receiving intermediate rehabilitation within three months since injury [171].

2.6.2 Intermediate Care Facility

Intermediate care forms part of the community-based service arm of the primary health care system, the entry point for most users into the public health care system in the Western Cape. Only two out of 25 intermediate care facilities in the Western Cape are paediatric facilities [168]. Next, the two paediatric intermediate care facilities are community based non-governmental institutions operating in partnership with the WCDOH. This continuation of rehabilitation care at this level, post- acute phase, aims to facilitate optimal recovery for ultimate transition back home and into society [172]. Intermediate care consists of subacute, rehabilitative, palliative and respite care to persons who are medically stable, but not ready to be discharged to their living environment yet [6]. This is according to the Landrum rehabilitation outcome levels, stating that physiological stability has been achieved (Appendix four). Once medical stability is established, transfer can then happen to an intermediate care facility, thereby relieving pressure on acute bed space [166]. The objective at an intermediate care facility is to facilitate optimal recovery that enable adults or children, to regain skills and abilities in activities of daily living [165]. The ultimate discharge placement is back home or alternative long- term placement if required. In other words, the objective is for the patient to reach the Landrum rehabilitation outcome level three and four. Rehabilitation goals within intermediate care are to reduce activity limitations and improve functional abilities for improved participation.

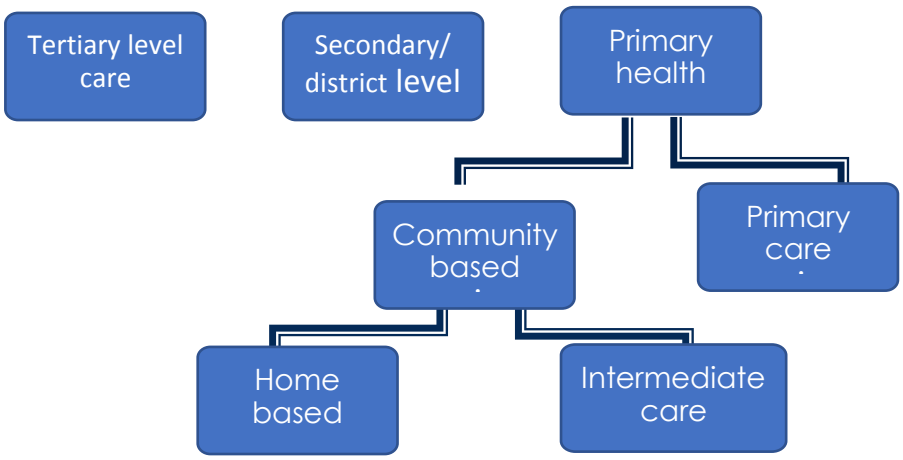


Figure 2-2. Depiction of WCDOH Primary Health Care Service

2.6.3 Physiotherapy: Timing and intensity of Intervention

Physiotherapists as part of the multidisciplinary team, direct therapy to enhance motor function [173] . The ICF guides the physiotherapist in adopting a holistic approach by relating motor ability to participation within relevant environmental contexts of the child's lived experiences [174]. Darrah et al. (2008) also stated that therapy goal setting includes the enhancement of participation in everyday living situations whether it is in the classroom, home, or community. In paediatrics, because the child is still developing, physiotherapy intervention incorporating strategies for learning and relearning of motor skills are encouraged [175]. However, a paucity in evidence exist to support the impact and efficacy of physiotherapy in children with acquired brain injury and there is no gold standard to guide choices in type of treatment, frequency, timing, duration and intensity of therapy treatments [176].

A delay in the initiation of a comprehensive rehabilitation program post-injury has been correlated with worse functional outcomes [24] though no guideline exists on when the optimal time is to initiate therapy [28]. Hence ,early intervention post an acquired brain injury is recommended for best clinical outcomes [28]. Galvin et al. (2011) concur, stating that interventions given within six months of injury onset yielded more functional gains compared to giving therapy after the 6-month period [105]. Patients were shown to better recover their functional capacity, when aggressive physiotherapy was given during the acute

phase post injury. The length of hospital stay was also shorter for these patients [43] and a shorter time frame between injury onset and improved functional outcomes may be related to a shorter time frame between injury onset and therapy initiation [177].

Historically, therapy dosage, intensity and length of stay are determined by the treating therapist based on clinical experience. Not having these guidelines in place have cost implications. Evaluating the effect of treatment dosage and intensity on functional outcomes might help to determine the length of stay required for optimal recovery to occur at a paediatric intermediate care [178]. The study by Jette et al. (2017) found no correlation between therapy intensity and functional outcomes in patients with traumatic brain injuries although in stroke patients they found that higher intensities of therapy yielded greater gains in functional independence and shortened the length of stay [179]. On the other hand, Chen et al. (2004) found that functional outcomes achieved post TBI were possibly related to the therapy dosage [180].

The bulk of the literature on the impact of physiotherapy on motor functioning in children deals with cerebral palsy, which generally has an earlier onset than TBI. High intensity physiotherapy is advocated to ensure the long term sustainability of functional outcomes achieved [31,107, 181, 182]. Interventions given two to three times per week led to improved gross motor function in patients with severe physical limitations. A study involving children with cerebral palsy (whose clinical presentation is like ABI) by Christiansen et al. (2008) indicated that similar results in motor outcomes are possible when applying physiotherapy intervention intermittently versus continuously [44]. They evaluated the impact of physiotherapy delivered within a 30 week period on the gross motor outcomes of children with Cerebral Palsy. Therapy was provided either four times per week for four weeks followed by a six weeks pause, or once or twice weekly. In this study both groups received the same amount of therapy sessions albeit at different time intervals.

Different opinions exist on whether increasing treatment intensity lead to improved motor outcomes in children. An improvement in gross motor outcomes in children with cerebral palsy was observed in the study by Trahan et al. (2002) which involved five children with severe Cerebral Palsy [183]. In their study physiotherapy was given intermittently over a six-month period, four times per week for four weeks followed by no therapy for eight weeks. Results indicated that gross motor function improved in all the participants and the

improvements were maintained during the rest periods. Bower et al. (2001) also recommend breaking up therapy intervention into portions with rest periods to prevent the possibility of children becoming non- compliant and drained [184]. In their study, a group of 56 children receiving therapy five times a week over six months were observed. They reported that motor outcomes are achieved when a patient centred approach is adopted in therapy. In a South African based study by Broughton (2014), found that an intensified block of five days of NDT improved the capacity of children cerebral palsy to participate in functional activities [45].

Therapists are encouraged to use validated and reliable outcome measures to inform and evaluate the treatment approaches they employ and to ensure that the goals achieved are aligned to the child's needs. There are many outcome measures for use in children and in choosing suitable measures it is important to align the measures with the different components of the ICF.

2.7 Caregiver involvement.

The event of a brain injury not only affect the child, but also have implications for the caregiver and family which could result in increased care associated strain [185]. Caregiver strain could be influenced by injury severity, injury cause and the caregiver's ability to cope with the consequences of the acquired brain injury [186]. Paediatric intermediate care rehabilitation facilities catering for the economically disadvantaged child is lacking in South Africa [49]. These conditions of limited access to health and rehabilitation services, result in unmet heath care needs, a contributor of caregiver strain [163]. In addition, parents might also deal with issues of isolation, social deprivation, loss of, or insufficient income, and lack of information on their child's condition and management (short and long term) [187]. In light of poor pre-morbid-socio economic circumstances, caregiver strain might be heightened post morbidly due to the added challenges presented by their child's condition [25]. Accordingly, a conducive environment that takes into account the social and economic diversities of the South African population, is recommended to support caregivers along the continuum of care, in order for optimal functional recovery to occur [25].

Burden related to care for a child with ABI led to less positive interactions and as a result, caregiver support is required to moderate the impact of caregiver strain on recovery [188]. The family environment and neuro-functional outcomes post brain injury has been a

research topic of several studies. A common trend was that the family's reaction, their ability to cope post injury, and the preinjury environment were thought to impact on recovery [188, 189]. Wade et al. (2008) conducted a series of studies involving children with TBI and orthopaedic injuries to evaluate the impact of injury on parent child interactions. In their one study in 2008, involving 193 young children aged three to seven with TBI (n=80) and orthopaedic injuries (n=113) indicated that parents of children with severe and moderate TBI display less affection towards their children compared to parents of children with an orthopaedic injury. This lack of warmth impacted negatively on the cognitive and behavioural recovery of their children [188-195]. In a recent longitudinal study, in 2016 by the same authors studied, the impact of the social environment on long-term functional outcomes post injury [167]. This time their study involved a group of 130 children post TBI and orthopaedics injury. Results showed that a permissive or authoritative parenting style, reduced functional and cognitive behavioural outcomes leading to subsequent problems in academic performance [196]. The authors concluded that family support should be on offer from the early acute phase post injury and continue throughout the recovery trajectory, in order to mitigate possible problems in cognition and behaviour from emerging.

Research exploring the relationship between the family environment and rehabilitation achieved in developed countries report similar findings of unmet healthcare needs as a common indicator of poor functional outcomes [189]. For example, Aitken et al. (2009) reported that unmet health care needs and poorer functional outcomes led to significant caregiver burden in their study cohort [189]. They examined the relationship between family and child functioning one-year post injury in children post TBI, aged five to fifteen years old. Hence, the impact on caregiver burden has to be considered in rehabilitation [185].

Socioeconomic factors impacting on rehabilitation access is one of the challenges facing the South African population [51,56]. The impact of the above mentioned caregiver strain in combination with poverty must be taken into account particularly in the Western Cape where 31% of children live in poverty stricken households [197]. Families with constrained resources are thought to experience heightened levels of stress associated with burden of care [154], which is compounded by the nature of care received by children with severe brain injury [163].

Overseas and local studies advocate for timeous access to rehabilitation, to reduce caregiver burden and thereby, fostering an environment to improve the child's functional capacity for optimal recovery to occur [51, 198]. Furthermore, timeous, ongoing and accessible rehabilitation services providing follow up and support might alleviate caregiver burden and alleviate functional barriers [52].

2.7.1 Health related quality of life tests

Many tools exist to measure caregiver burden related to various conditions and the impact of health on quality of life.

2.7.1.1 Caregiver Strain Index (CSI)

The Caregiver Strain Index (CSI) is a 13 item measurement tool used to screen and evaluate parenting issues that might lead to parent and child behavioural problems [199]. It is also short and quick to administer. The CSI was developed by Robinson in the 1980s to evaluate strain experienced by families caring for elderly patients post hospitalisation [200]. The CSI has also been found to be valid and reproducible in measuring caregiver strain in caregivers of stroke patients and is frequently used in this regard [201]. The 13 item scores were derived as follow: 10 from common stressors experienced by adult caregivers of the elderly and 3 potential stressors identified by literature review. Each of the 13 items describes a stressor and gives an example of a situation that depicts the stressor. A yes (1) or no (0) response is required. The 0 and 1 responses are added for the 13 items, giving a range of scores from 0 to 13. Robinson et al. (1983) obtained an internal reliability of Cronbach's alpha of 0.86. A score of 7 indicates a high level of caregiver burden [10]. Chen et al. (2002) recommends the use of repeated measures when using the CSI for a reliable measure of caregiver strain experienced [202]. Validity of the index was found to be 0.41 and test-retest reliability 0.75. While the Cronbach's alpha value of the index for first administration was 0.77, it was found to be 0.73 for the second administration [203]. The CSI was validated (internal consistency of 0.8) for use in a group of caregivers of children with Cerebral Palsy in Zimbabwe [204].

2.7.1.2 EQ5DY proxy version

The EQ-5D-Y measures the health-related quality of life for children and adolescents. It was developed specifically for the use in children [2056]. In the event that a child does not have

the capacity to answer the questions, a proxy version is available. A caregivers who are familiar with the child is then approached to answers the question on how they view the child's health at the time of the interview [206]. Feasibility and validity for children with functional motor disability was found [207].

The EQ-5D-Y has two proxy versions: [208, 209]

• Proxy 1: The proxy rates the health of the child according to how he or she would describe the health of the child.

• Proxy 2: The proxy rates the health of the child according to how he or she thinks the child would describe his or her own health.

The Proxy version 1 is recommended for children aged four to seven years and for the child eight years and above if they are unable to fill in the EQ-5D-Y themselves.

The EQ5Dy proxy version is divided into two components:

1. The EQ5DY proxy version is a descriptive system consisting of the same five dimensions as in the EQ5DY namely Mobility, Looking after Myself, Doing Usual Activities, having Pain or Discomfort, Feeling Worried, Sad and Unhappy [208]. The caregiver responds to these questions by selecting no problems, some problems or a lot of problems to indicate their view of the child's health state.

2. The EQ visual analogue scale (EQ VAS). This is a vertical scale on which the child's health state is rated by their caregiver on a scale of zero to 100. 'The worst health you can imagine' is represented by zero and 100 'the best health you can imagine'.

A study involving sample populations of children and adolescents from South Africa, Sweden, Spain and Germany have established the validity and reliability of the EQ5DY [208, 210, 211]. A limitation of the EQ5DY Proxy version is that it is available in English only. Some research suggests that self-report can be used for children ages five to 14, with parent proxies providing data when the child is unable or impaired without significantly compromising the quality of the data, but parent and child responses might also differ. For example, one study on the use of parental proxy data among injured children found that children tended to rate their HRQL significantly higher than the ratings of their parents in the short term, while in the long term the ratings converged [212].

2.7.1.3 The Family Needs Questionnaire

The Family Needs Questionnaire consists of 40 items to measure the perceived needs of families during recovery from acute to post-acute post brain injury [213]. Need importance and need met is evaluated. Importance is measured on a scale of not important, slightly important, and very important, whereas a no, yes or partly is assigned to need met. The measure was adapted to assess the needs for the caregivers of children [214].

2.7.1.4 Pediatric quality of life inventory (PedsQL generic core).

The PedsQL generic core measures quality of life in physical, emotional, social, and school functioning dimensions [186]. Cognitive and general fatigue is evaluated on a multidimensional scale. It is a 23-item measure. A summary score for physical health and a total score for psychological health is computed. A score of 100 indicates no difficulties and lower scores indicate increasing difficulties. Children aged five to 18 years can complete self-reported forms. A parent proxy version is also available if the child is aged two to 18. Validity in children with traumatic brain injury (TBI) is established [186, 215]. The test is quick taking five minutes.

2.8 Conclusion

The epidemiology and impact of ABI is not well documented in South Africa in general and Cape Town in particular. There is some debate as to whether age at onset is related to final outcome, as well as to the optimal time to initiate and continue physiotherapy. The course of resolution of the functional problems, due to resolution of the insult and neural reorganisation has also not been mapped.

The GMFM might be an appropriate tool to use for measuring change in motor function in children with ABI, although primarily developed for children with cerebral palsy. The EQ-5D-Y has been validated within the context of the Facility and might give useful information regarding changes in the HRQoL of the children over time. In terms of the environmental factors and participation, the mental health and quality of life of the caregiver are important, both as an outcome of therapy and as a determinant of change. The CSI might also be applicable for use in the current study group, because validity has been established in a comparable group of care givers of children with physical disabilities coming from similar socioeconomic contexts.

Chapter 3. Methodology

3.1 Introduction

Descriptive observational studies can provide useful information regarding the association between different variables [216] and can provide information for include trend analysis, health-care planning, and hypothesis generation. Cohort studies have been identified as the best method for determining the incidence and natural history of a condition [217] and this design was thus chosen as the most appropriate method of meeting the objectives of this study.

A longitudinal, prospective cohort design with repeated measures was employed. With this type of study all participants are assessed as one population sample using the same outcome measures at different time points. All the measures were done at Baseline and repeated at Week three (end of first cycle of intervention), seven, nine and Week thirteen.

The research setting was described in Section 1.2.

3.2 Participants

The study sample was one of convenience in that all children and caregivers who were available and eligible for the duration of the study were enrolled. The person primarily responsible for the daily care of the child was defined as the caregiver. The initial recruitment took place from May 2016 to October 2016 and data collection continued until the end of January 2017.

3.2.1 Inclusion and exclusion criteria

Children, between two to 14 years, with an acquired brain injury sustained within eight or less months and who were medically stable were included. Medical stability is a requirement for admission to an intermediate care facility [6]. A child is termed medically stable when their health condition is stable and they no longer require acute medical care [218], in other words Landrum outcome level one has been achieved [219] (See Appendix 4). In addition, the child participants needed to have the ability to participate in a therapy programme for at least 1 hour daily and caregiver consent had to be obtained. The caregivers needed to understand English, because the outcome measures employed were in

English. When caregivers however struggled with a question, then a Xhosa speaking interpreter was available to them or the research assistant would read and explain the question to them. A Xhosa speaking interpreter was also used during the GMFM assessment sessions when the child had a limited understanding of the English instructions of the GMFM. Instructions for the GMFM were given in Afrikaans by the research assistant when Afrikaans was the primary language of the child. Previous therapy or degree of severity of injury did not result in exclusion.

Children were excluded based on their medical information on admission. Exclusion occurred if the medical records of the child stated that the child:

1. Experienced intermittent seizures that were exacerbated by movement and if they had planned surgery during the intervention period.
2. Had a neurodegenerative condition, cerebral palsy, or progressive brain tumour as the instability of the condition could influence the child's performance.
3. Sustained associated fracture(s) preventing the child from participating in the programme.
4. Had active TB meningitis or HIV encephalopathy due to the medical care required for management of the condition.
5. Had a low level of consciousness or were in a vegetative state based on information in their medical files and input received from nursing personnel. A Glasgow Coma Scale lower than 15 were viewed as a low level of consciousness, indicating that the child was not fully awake and therefore full active participation was not attainable.

3.2.2 Sample size determination

It was anticipated that there would be approximately 17 children who would meet the criteria for admission during the six-month period of recruitment based on previous admission records. The sample size to detect a small to medium effect size of change in GMFM88 between the four-time points of measurement was calculated. The sample size required was 18, based on parameters outlined in Table 3.1. The anticipated sample size would then be large enough to support the use of ANOVA for repeated measures to detect differences in scores between the different time points.

Table 3-1: Sample size calculation

Input Parameters			Output Parameters		
	Effect size f	0.21	Non-centrality parameters ג	15.88
	α err prob	0.05	Critical F	2.79
	Power (1 –β err prob	0.90	Numerator df	3.00
	Number of groups	1	Denominator df	51.0
	Number of measurements	4	Total sample size	18
	Correlation among measures	0.8	Actual power	0.91
	Non-sphericity correction ε	1		

GPower Version 3.1 Faul, F: Universitat Kiel. http://www.gpower.hhu.de/en.html

3.3 Instrumentation and measurements

Based on the International Classification of Functioning Disability and Health (ICF) framework, outcome measures were identified to measure functional activities and participation restrictions. The impact of caring for a child with a disability was regarded as being an environmental factor from the child's standpoint as it might affect the support for and attitude towards the child by the caregiver. The Gross Motor Function Classification scale (GMFCS) was used to classify the motor function and the Gross Motor Function Measure88 (GMFM88) was used to assess changes in the child's gross motor function (activity limitation). The questions of the Paediatric Evaluation of Disability Inventory (PEDI) and EQ5DY proxy version (participation restrictions) were posed to the caregivers by the research assistant, whereas the Caregiver Strain Index was filled in by the caregivers (contextual factors – support from caregivers). As the measures were not all available in local languages, the English versions of the caregiver report instruments were used, as per the inclusion criteria. However, interpreters were available for testing the motor function of children who were not fluent in English.

3.3.1 The Gross Motor Function Classification System (GMFCS)

The researcher has over 20 years of experience in working with children with gross motor difficulties. The researcher also has prior experience in using The Gross Motor Function

Classification System and GMFM88 in children with gross motor difficulties and has attended workshops, talks and lectures on the use of the GMFCS and GMFM88. Based on this expertise, the researcher did the classification of the children's level of gross motor function based on observation of the child's abilities in every day settings at the Facility. Input received from nursing personnel and therapy staff at the Facility was also considered during the classification process. The child was matched to the classification level that best described their abilities and limitations in gross motor function. A similar process was described by Palisano et al. (2008,) in classifying children with cerebral palsy using the GMFCS [8, 220, 189].

3.3.2 Gross motor Function Measure 88 (GMFM88)

The GMFM88 (Section 2.3.5.2) was chosen as it has been used with children with TBI and found it to be a reliable tool in measuring minimally detectable change in motor function [109]. Although the GMFM66 can yield scores on an interval measure using the Gross Motor Assessment Estimator (GMAE) [64], it is only recommended for use in children with cerebral palsy as it is standardized for use children with CP and because of possible ceiling effects [38]. The GMFM88 was thus selected as the measurement of choice in the study. The inter-rater reliability in scoring the test items of the GMFM88 was established between the research assistant and the study researcher via a small pilot study involving three patients fitting the study inclusion criteria. A correlation of rho=0.99 was achieved which indicated that the instrument was reliable within the study context.

All the GMFM88 measurements were conducted by a research assistant who was blinded to any information relating to the child. Testing was done after a one-week period after admission (Baseline). Follow up measurements took place at weeks 3, 7, 9 and 13 post Baseline assessments. Time taken for administration of each test measurement of the GMFM88 varied between 20 to 50 minutes per child. Testing time was generally shorter for children with GMFCS level five, compared to children with classification levels one to four. During each testing session, the child's best performance of the test item was used to score the child's ability according to the guidelines stipulated in the GMFM88 manual [222].

Testing took place in the physiotherapy department at the Facility. The department was equipped and fitted with the tools required to perform the test items. Equipment included a therapy mat, bench with the height requirement stipulated in the GMFM88 manual, toys to

motivate the child to perform test items, stairs with five steps, two parallel lines and a circle on the floor according to the dimensions stipulated in the manual. The children were dressed in comfortable clothing. Short breaks were given to the children if they became tired. A rehabilitation care worker or the caregiver assisted the research assistant when testing a Xhosa speaking child. Caregiver assistance was also utilized for Afrikaans-speaking and English-speaking children, if they were available.

The research assistant scored the children's ability per test item and calculated the total gross motor score and total percentage for each child at all the test intervals.

3.3.3 The Pediatric Evaluation of Disability Inventory (PEDI)

The Pediatric Evaluation of Disability Inventory (PEDI) (Section 2.3.4.3) was chosen to assess the children's functional performance and participation restrictions, on pragmatic and scientific grounds. The PEDI had previously been used and was available at the Facility. The instruction manual and the PEDI had been purchased by the Facility therapy department with the aim of providing evidence for service delivery. The inter-rater reliability had been established in other studies as being satisfactory (interclass coefficient of 0.95 -0.99 [111] and inter respondent validity interclass coefficient of 0.64 to 0.74 [116]) and this supported the choice of this instrument. Other considerations were the flexibility and ease (no equipment required) of administration of the PEDI and that it can be administered by caregiver reporting, professional reporting or a combination of observation and reporting [118]. The instrument has not been reproduced for copy-right reasons, but the items are listed with the raw scores in Appendix 8.

The research assistant conducted an interview according to the guidelines set out in the instruction manual with the caregiver in the therapy department waiting area, the physiotherapy department, or in the ward. Functional performance reported by the caregiver was scored in the Mobility and Self-Care domains. The Self-Care dimension consists of items evaluating activities of daily living such as eating, dressing, grooming and personal hygiene [116]. Whilst, the mobility domain consists of activities evaluating capability in transfers, indoor and outdoor mobility and stair climbing. Items are scored as present or absent. The PEDI was conducted on the same day as the GMFM88 measurement. The interviews varied between 20 to 30 minutes. The research assistant scored the child's ability to perform a task dichotomously (one or zero) according to input given by caregivers.

The researcher tallied the total of the item scores per domain tested and calculated the scaled scores of each domain.

3.3.4 Care giver Strain Index (CSI)

The Caregiver Strain Index (CSI) (Appendix 7; Section 2.7.7.1) was chosen to assess the health related quality of life of the caregiver, because it is quick, concise and easy to administer and has been found to be valid and reliable in evaluating caregiver strain [223]. Although it was developed to assess burden associated with care of the elderly with cancer [224], the measurement has been used in other conditions and in children with neurological impairment [225]. In addition, it was used successfully in an African context and found to be an appropriate measure to gauge the impact of caring for a child with cerebral palsy [225] The English version of the Caregiver Strain Index was used based on caregiver's report that they felt comfortable in answering the questions in English. Repeated measures were employed to ensure that the caregiver strain assessment was reliable as proposed by Chen et al. (2002) [224].

An explanation on the purpose of measuring caregiver strain was provided to the caregiver at recruitment. The process on how to fill the CSI in as well as the measurement questions asked were explained verbally to caregivers before they completed the CSI form. A brief written instruction on how to fill in the CSI was also given to the caregiver every time they completed the form. The caregiver completed the CSI forms on their own at the Facility or they took it home with them. Once completed the form was collected or they sent the completed form to the Facility. A score of seven or more indicates a high strain level [69].

3.3.5 EQ-5D-Y proxy version

The EQ-5D-Y proxy version (2.7.3.2) (Appendix 7) was used in this study, because the children participating in the study all had a moderate to severe acquired brain injury and did not have the cognitive capacity to fill in the EQ-5D-Y. Cognitive capacity was gauged on input given by their caregivers, and the staff on their ability to make informed decisions. Additional information on their social behavior and intellectual functioning obtained from the caregiver, staff working with child and teachers were considered, to determine the child's capacity to make informed decisions.

The EQ-5D-Y proxy version was given to the caregiver by the research assistant on the same day as the GMFM88 and PEDI to fill in or if the caregiver was not available, at least within the same week. An explanation on how to fill in the EQ-5D form and guidance on how to complete the questionnaire was provided by the research assistant on the day of completion. The caregiver identified the item that they felt best described their child's, in order to reflect the child's current health related life.

3.3.6 Socio-economic conditions

Information on the environmental factors related to living conditions of the children in terms of the marital status of the parents, siblings, extended family, and their ages, were obtained from admission records and intake interview notes that are performed as standard at the Facility during admission. Information on living condition, caregiver employment status and access to social grants were obtained from the Facility social work, medical and admission records.

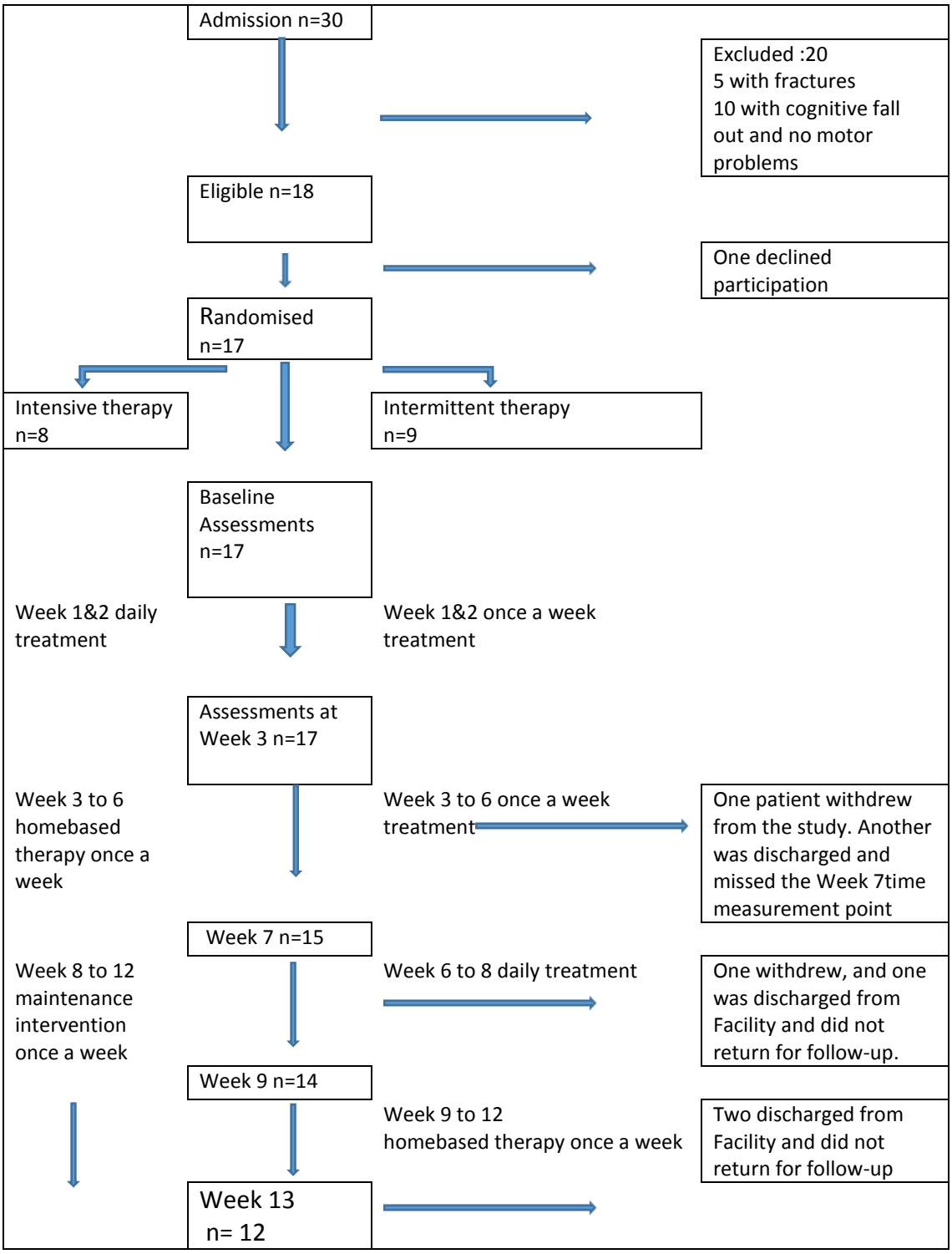
3.4 Recruitment and Procedure

Permission to conduct the study was obtained from the Human Research Ethics Committee University of Cape Town Health Faculty (ref 831/2015) (Appendix 8.5). No consent was needed to conduct the research study at the Facility, because the Facility management requested the study. An information letter was forwarded to the staff at the Rehabilitation Departments of the three main tertiary hospitals in the Western Cape to inform them of the study and to request them to refer suitable patients (Appendix 8.6), because they were the main sources referring children with ABI to the Facility. In addition to the letter informing referring hospitals of the study, the researcher approached the heads of the therapy departments at the three tertiary hospitals in the Western Cape to give them a verbal explanation of the study and to ask for their assistance in identifying and referring appropriate patients for rehabilitation to The Facility. The same procedure of referring patients to an intermediate paediatric care facility was used. An information sheet was given to the departmental heads to inform them of the project's objectives, aims, the methodology, projected possible outcomes, and a copy of the ethics approval certificate, in order to enlist their support. A description of the study population with inclusion and exclusion criteria were also provided.

After admission to the Facility, the researcher reviewed the child's medical records and observed the child in the ward, to establish suitability for recruitment to the study. The researcher then approached the caregiver (the parent or legal guardian of the child) one week after admission to inform them of the study. Information on the study design, outcome measures employed, objectives, benefits, and risks of the study were shared with the caregiver. During this process, considerations of the ethical principles relating to autonomy, informed consent, and assent, confidentiality, non- maleficence and beneficence were considered and applied (See Section 3.6). The caregiver was given the opportunity to ask any questions related to the study and these questions were answered to the best of the researcher's ability. A written explanation of the study was then provided to them, which they could keep. The written consent forms (Appendices 8.1 and 8.2) were attached to the information sheet for them to fill in, should they decide to agree to their and their child's participation in the study. Once the caregiver agreed to participate in the study and the letter of consent was obtained, an option to attend the programme on an inpatient or an outpatient basis was given.

A pilot study to test the methodology was conducted prior to the main study. It involved three participants referred for rehabilitation at the Facility meeting the inclusion criteria with GMFCS levels two to four. The protocol followed in the pilot study was the same as that used in the main study. The aim of the pilot study was to test the intra-rater reliability between the research assistant and the researcher's performance in administering the GMFM88 measurements. Training on how to conduct the GMFM88 and how to administer the PEDI, EQ-5D-Y proxy version and the CSI was given to the research assistant, a registered physiotherapist, before the pilot study commenced. The administration manuals of the outcome measure were given to the research assistant to read and obtain knowledge and understanding of measures. Practical demonstration on how to administer each outcome measure was given by the researcher. Case studies in the PEDI manual on how to use PEDI, were also utilized as references during training. After the research assistant was observed administering the outcome measure, a discussion and feedback session occurred. The pilot study took place at The Facility. The pilot study indicated good intra-rater reliability (rho= 0.99, almost perfect agreement) between the blinded assessor and researcher score of the

total GMFM88. Other findings of the pilot study were that the GMFM88 was reliable in measuring change over time in the patient's functional abilities.



During the research study, each participant was required to be in the study for a period of 13 weeks. Qualified physiotherapists and therapy students under supervision provided the interventions. On entry to the study, an option of attending the programme as inpatients or as outpatients to the Facility was given to participants. The caregivers of all the children (n=17), chose to have their children admitted as inpatients until after their intensive intervention were complete. Participants with the same gross motor function classification levels were paired once entered into the study. Randomisation techniques were applied to assign the children into an intensive or intermittent treatment group by asking caregivers to draw a card from an envelope. Baseline measurement scores were done within one week of entry into the study for both groups. The blinded research assistant assessed the children's gross motor function using the GMFM88 as an outcome measure and, as explained under section 3.3.3, interviewed the caregivers to fill in the PEDI. The EQ-5D-Y proxy and the CSI were given to the caregivers to fill in or alternatively the questions were read to them on their request. The caregiver selected the score they thought best described the child's and their quality of life. The intensive treatment group commenced with their daily two-week physiotherapy regime, within a week of the Baseline assessments. After that they were discharged with a home programme and received maintenance therapy from Facility rehabilitation care workers for four weeks. This group then received no physiotherapy intervention via a professional for the next six weeks after discharge.

Intensive therapy consisted of a 45 minute to an hour physiotherapy session given daily over a two-week period. In addition to the individual physiotherapy treatment, participants were slotted into group therapy sessions such as language stimulation, activities of daily living, gross motor, and hydrotherapy groups. During the intensive therapy programme, caregivers were requested to attend at least two training sessions. The training sessions provided caregivers with information on the child's condition and how to encourage and assist the child's participation in daily activities. Caregivers were also provided with opportunities to practice these during the therapy sessions.

The children, assigned to the intermittent group, stayed on at the Facility as inpatients and received physiotherapy once weekly for six weeks. After that they commenced with their two-week intensive intervention in Week 7, were discharged in Week 9, and after that also received maintenance therapy from the RCW for four weeks.

Caregivers of all the participants either stayed in at the Facility during the time of their child's admission or they travelled in on the days of the assessments. Transport money was given to caregivers traveling to the Facility or they made use of the Facilities transport. In the event that a caregiver did not arrive on the assessment days, the researcher would make telephonic contact with the caregiver to encourage them to attend the next assessment session. Alternatively, the Facility auxiliary social worker called the caregivers to encourage them to attend the next follow-up measurement dates. Reminders were also given to nursing staff to give to caregivers should they visit their child during visiting hours. Reminders were also sent home with the child during weekend leave, because the children all went home over weekends.

Transport money was given to caregivers to access the Facility for the duration of their participation in the study. Accommodation was also available to caregivers who wanted to stay in during the study period. Caregivers were requested to attend at least two training sessions during the study, one halfway and one at the end of the daily treatment regime. The GMFM88 assessments were performed by the research assistant, who was blinded to the interventions. Scores for the PEDI was obtained via an interview by the research assistant with the caregiver. The EQ-5D-Y was filled in by the caregivers and the research assistant assisted when clarity was needed. The CSI was filled in by the caregivers. Assessment dates differed, because participant recruitment was staggered. The Baseline assessments of the first set of participants were conducted on the 19th of May 2016. The last set of participant's Baseline assessments took place on the 16 of October 2016 and their final measurements were completed on the 22nd of January 2017.

All the GMFM88 evaluations were performed in the therapy departments of the Facility. Evaluations included Baseline assessments prior to the two weeks of daily physiotherapy, reassessments in Week 3 at the end of the two-week intervention cycle and reassessments at Week7, 9 and 13. Physiotherapy interventions took place at the therapeutic departments of the Facility. The one group (intensive) received daily physiotherapy for two weeks from the outset, totalling 10 physiotherapy sessions. The other group (intermittent) received weekly physiotherapy for the first six weeks, totalling six physiotherapy sessions, followed by a two-week period of intensive therapy. Occupational and speech therapy were given twice weekly to the intensive group and weekly for the intermittent group. Physiotherapy

interventions were similar for both the intensive and intermittent group and included strength training, task specific training, neurodevelopmental therapy, therapeutic standing, balance and coordination, gait retraining, prescription of assistive and mobility devices, training on the use of mobility and assistive devices and hydrotherapy.

3.5 Statistical Analysis

Non-parametric statistics were used throughout analysis, because of the small sample size. Descriptive statistics were used to describe the sample. As the sample was small percentages were not used as they could be misleading with small numbers. Chi-square tests were used to test for independence between the gender, diagnoses and GMFCS. We originally intended to use multiple regression analysis to establish the determinants of change but as the sample size was too small to support the inclusion of more than one or two variables, bivariate analysis was done instead.

The GMFM88 was the primary outcome measure and the change in score over time was used as the dependent variable in investigating the determinants of improvement. The total GMFM% score was calculated by totalling the sum of the GMFM dimension percentage scores and dividing it by five [222]. Scatterplots and Spearman's rho were used to investigate the correlation between changes in GMFM88 score from Baseline to Week three and the age of the child, time since injury and Baseline GMFM88 score. The Kruskal Wallis ANOVA for ordinal data was used to establish whether there were differences in all the outcome measures at the different time points and, if significant, a post-hoc Sign test was done to see where the differences lay. The effect size was calculated as recommended in the SPSS Survival manual [226] by dividing the z value by the square root of the total number of observations at both time points. Cohen classification of effect sizes as small ($d = 0.2$), medium ($d = 0.5$), and large ($d \geq 0.8$) were used. As multiple regression analysis is held to need at least ten responses per independent variable, this was not done due to the small sample size. However, simple regression analysis was done to establish how much of the variance in the Week nine score was attributable to the Baseline GMFM88% score.

3.6 Ethical Considerations

Ethics clearance was obtained from the University of Cape Town Human Research Ethics Committee (Appendix 8.5) to conduct the study. Caregivers of children with an acquired

brain injury are particularly vulnerable, because they often struggle to cope with the “loss” of a typically developing child. It was therefore important to consider ethical issues of beneficence, non-maleficence, confidentiality, justice risks and benefits during the study implementation. Language use was confined to simple, short instructions augmented by demonstrations by the assistant to accommodate for any cognitive problems that the child might have.

3.6.1 Autonomy

All participants were recruited voluntarily. No one was coerced into the research study. A decision to withdraw from the study could be made by participants at any time without fearing that it would impede on their access to rehabilitation in the future.

Informed consent was obtained from all the caregivers (Appendix 8.1.). Although a detailed simple explanation on the reason for the study, risks benefits, and participant’s role was given to the participants, none of the child participants were able to give assent due to their decreased level of cognitive function. Cognitive function was determined by the child’s ability to answer questions posed, input received from caregivers and clinical staff working with the child. Participation was voluntary with no coercion to partake in the study. Lunch and transport money as required were provided with no other incentives. Withdrawal from the study did not impede future access to rehabilitation service at the Facility.

Participant confidentiality was observed. No participant names are included in the thesis or any articles that might be published in the future. The name of the Facility will also not be included in any publication.

3.6.2 Non-maleficence

A consequence of an acquired brain injury is motor fall out and cognitive deficits. Great care was thus taken to ensure that the testing environment was safe, child friendly and hazard free to minimise falls and injury. To minimise risk, the therapy area was organised to reduce the chance of falling over objects or slipping. Non-slip therapy mats were used to cushion any falls and for floor activities. In addition, the assessor ensured that she was always close to the child to cushion or prevent a fall if necessary. The observational assessments were carried out by a trained blinded assessor and the intervention was provided by qualified

professional therapy staff and students under supervision. Breaks were given to children when required.

3.6.3 Beneficence and justice

Intensive daily physiotherapy was available to all participants albeit at different time intervals. Caregivers gained knowledge and training on how to facilitate their child's participation in everyday activities. The following ethical considerations when providing rehabilitation to the children were taken.

1. A need driven approach was adopted, to ensure that the rehabilitation provided was relevant to the patients need to be actively involved in therapy and transfer the skill learnt into their daily living environments.
2. Therapy was focused on improving quality of life and function.
3. The burden of care was taken into consideration during planning and implementation of interventions.
4. An integrated approach was advocated. Parents and, where possible, the child were encouraged to be part of decision making and to guide the therapist in treatment goal setting.

Chapter 4. Results

4.1 Recruitment

During the recruitment period a total of 30 children with an acquired brain injury were admitted to the Facility of which 18 children were eligible for recruitment to the study. Of the eligible children, one caregiver declined to participate in the study and 17 participants were thus recruited. There was some attrition and by Week 13, five children were not assessed (Figure 4-1).

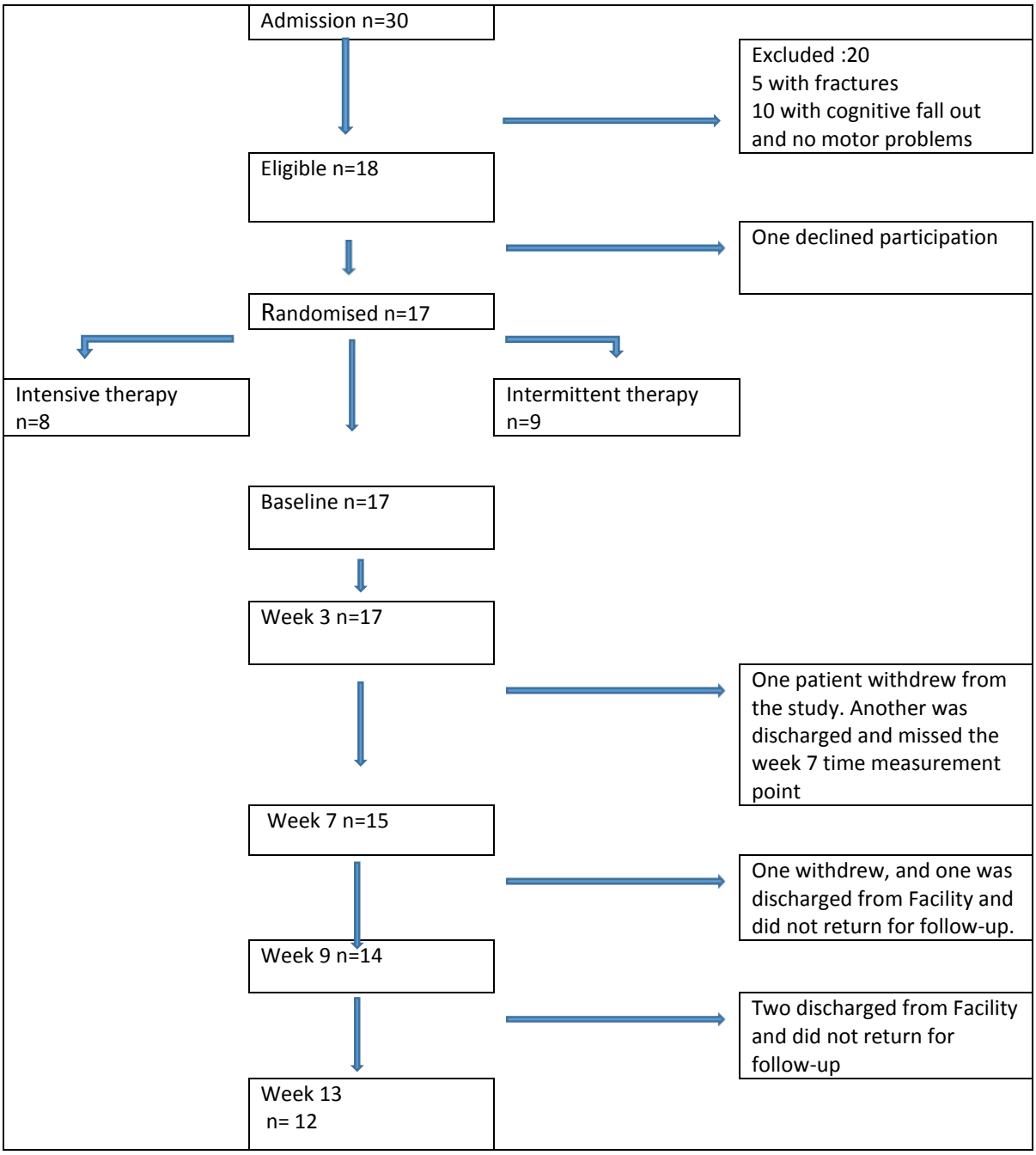
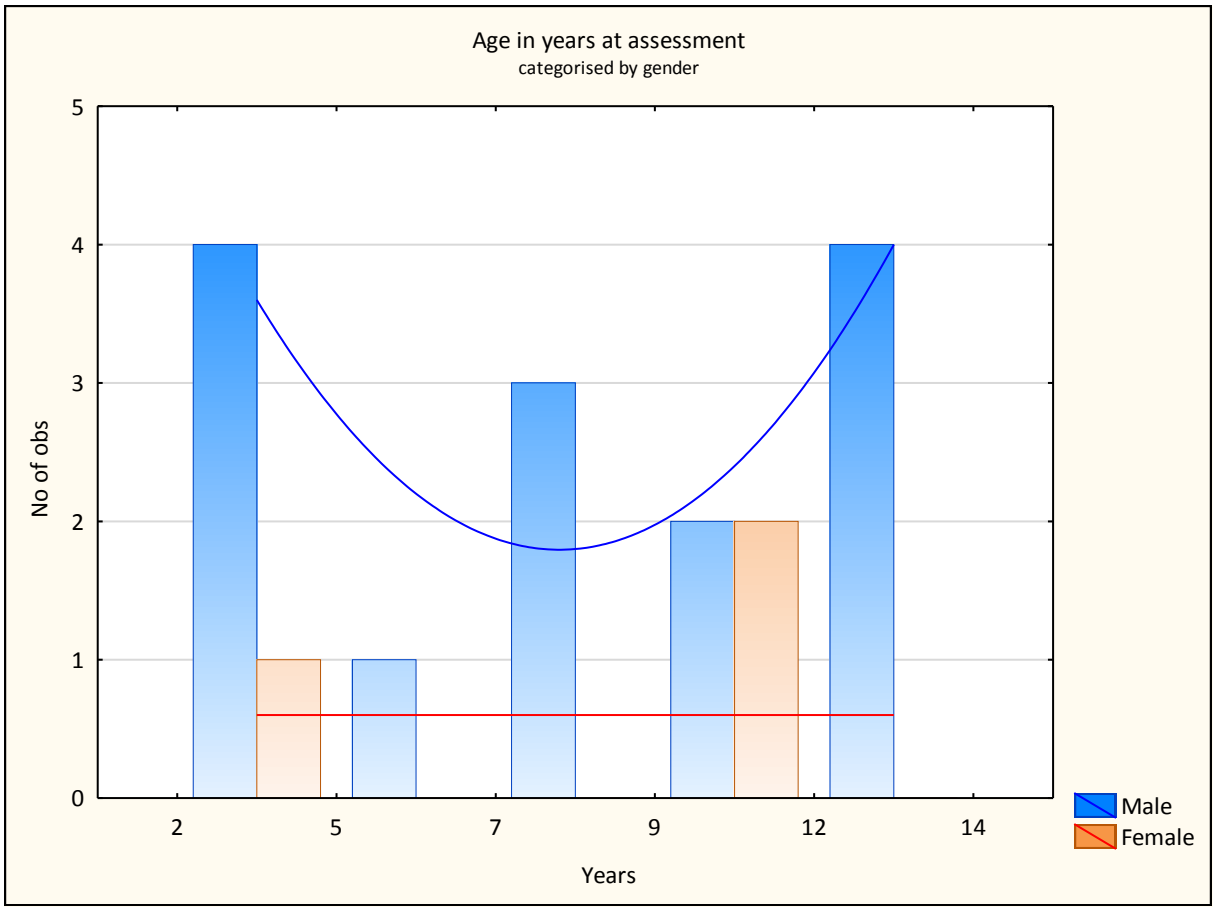


Figure 4-1: Flow chart of recruitment and attrition

4.2 Demographic and contextual background

There were three girls in the sample and the median age of the children was 9.1 years (range 2.1-14.0). The histogram below showed that the distribution for the boys was bimodal with more children below four and above 12 years of age (Figure 4-2).

Figure 4-2: Histogram of age



Males N=14, Females N=3 Category boundaries x-x.99

Table 4-1 describes the living conditions of the participants. Nine of the children lived with either a single parent or grandparents, six came from homes in which no one was employed. In eleven of the households, either the mother or the father provided income through employment (four mothers and seven fathers in the eleven households).

Table 4-1: Environmental factors relating to living conditions

Child	Socio economic conditions/ type of housing	Employment status
1	Mother and Father separated. Mother lives in Eastern Cape. Father primary caregiver. 2 Siblings of 14 and 8 years old Receives child support grant. Informal dwelling.	Mother unemployed. 39 years of age. Father works as a casual labourer. 42 years old
2	Single Mother No social concerns. Lives in backyard of maternal grandfather. Informal dwelling. Has medical aid.	Mother employed
3	Father deceased. No siblings. Stays in a bungalow in the backyard of the maternal grandparents. Sanitation facilities are in main house. Receives a child support grant	Mother worked, but gave up employment to look after her child after the accident
4	Has 2 siblings of 9 and 3years. Renting a flat. Maternal grandfather is supporting family. In receipt of child support grant. Indoor sanitation.	Parents both unemployed Mother 28 years of age, Father 27 years old
5	14-year-old sibling. Informal housing. Receives a child support grant.	Mother housewife Father employed part time.
6	Father not involved with family. 4 siblings. Mother remarried; but second husband passed away in 2016 Informal housing; back yard dwelling- one room house. Sanitation in main house. 4 child support grants	Mother unemployed.
7	Stays with maternal grandparents. Self- owned RDP house. Receives child support grant. Father passed away. Mother unemployed and has a 2-month-old baby and another 7-year-old child.	Grandmother unemployed. Supported by grandfather who is a seasonal worker
8	Has 2 Brothers, tik (crystal methamphetamine) users. Lives in self-owned house. Maternal aunt stays with them. Helps with income. Receives child support grant.	Father works 3x per week. Mother housewife
9	2 siblings- 14 and 1yr Has medical aid. No grants	Mother unemployed. 32 years old. Father employed.
10	No grants. 1 sibling of 5 years. Lives in informal housing Household income below R4000pm	Mother and Father employed. Mother 34 years old. Father 39 years old. Part time shift worker
11	Stays with Mother. Father visits. Informal housing. Outside sanitation. Receives child support grant. Household income below R4000pm	Mother unemployed
12	Two older siblings 9 and 14 years. Self- owned house with indoor sanitation. Receives a child support grant. Household income below R4000pm	Mother unemployed Father works.
13	Two younger siblings, 9 & 3 years. Mother pregnant. Informal housing. No grants. Household income below R4000pm	Mother works. Stopped working when baby was born. Father unemployed
14	4 siblings 19, 17, 9 and 3 years old. Informal housing. Outside sanitation. Three child support grants.	Father works part time. Mother not working

15	Lives with mother, maternal grandmother, sister, the sister's husband, uncle, aunt and two cousins. Mother has epilepsy and receives a disability grant. Father is married to someone else. Doesn't have much contact but pays support. An application for care dependency grant was done at GSH. Receives a child support grant. Low cost housing	Mother not working. Older sister works
16	Lives with mother, maternal grandmother and uncles. Father is not involved. Has a 6 years old sister and a 5 years old brother. Mother looks after grandmother who is wheelchair bound. Mother started working as a car washer on 4/4/2016. Informal housing. Receives a child support grant.	Just started working at time of her child's admission to the facility still on probation.
17	Mother stays with brother who supports them. No siblings. Receives child support grant. Household income below R4000pm. Informal housing	Mother employed

The majority, ten, stayed in informal housing or in backyard dwellings and thirteen received child support grants. Most (14) had older or younger siblings and eight lived with extended family, who appeared to support the family financially. One mother was herself disabled, another had to care for a wheelchair bound grandmother and in one family two of the brothers were substance (crystal methamphetamine) abusers.

Prior to the injury, approximately one third of the participants were pre-schoolers (6), four children were in the foundational phase Grades 1-3 and seven were in the intermediate phase of schooling Grade 4- 7 (Table 4-2).

Table 4-2: Level of schooling achieved (Grade)

Grade	Count	Cumulative Count
Preschool	6	6
1	3	9
2	1	10
4	2	12
6	1	13
7	4	17

4.3 Aetiology

There were 13 children who had traumatic brain injury, of which seven were pedestrians, two were passengers, three had non-accidental injury and one had fallen. The remaining four had acquired their injury through infection (Table 4-3). Those with non-accidental injury were the oldest boys.

Table 4-3: Cause of injury

	Gender M	Gender F	Row Totals	Age range
TBI –Pedestrian Motor Vehicle Accident*	7	0	7	6.1-13.8
TBI –Passenger Motor Vehicle Accident**	2	0	2	3.6-3.8
Non-accidental injury (Blunt trauma, stabbing)***	3	0	3	11.4-13.5
Infection (one unknown, encephalitis and a viral infection)	1	3	4	2.3-9.9
TBI fall*	1	0	1	2.2
Totals	14	3	17	2.2-13.8

**unsupervised, at home.*

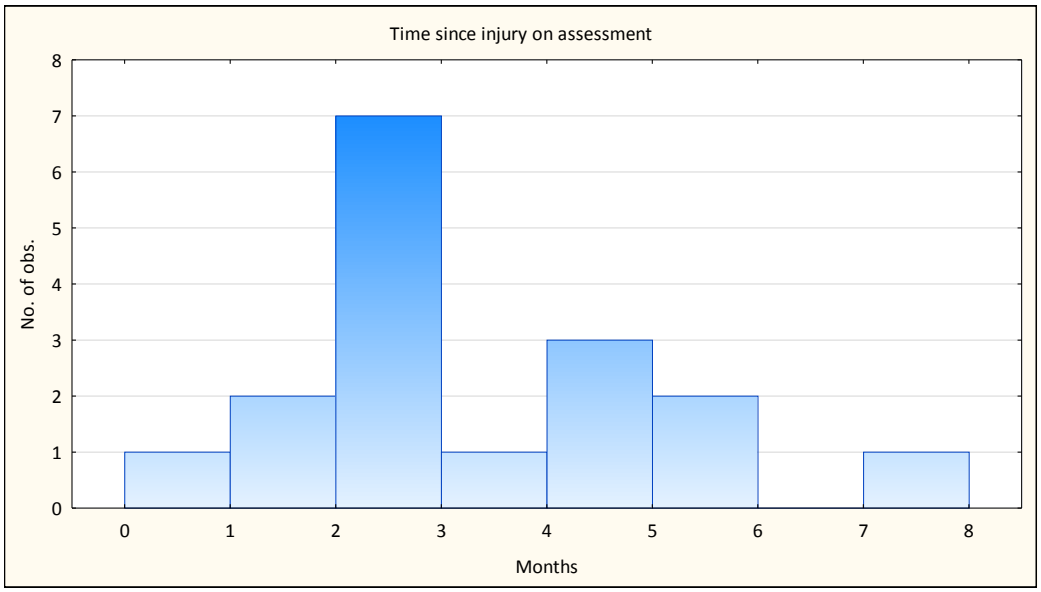
Clinical notes indicated that the girls all sustained their injury due to an ischaemic event secondary to an infective condition or malformation. On admission they presented with unilateral hemiplegia, ataxia and an inability to walk independently. Recovery in this group was rapid and they started out with high Baseline GMFM scores above the 70th percentile. The cause of injury was not independent of gender and no girls acquired damage through a traumatic event. (p=.006, (Table 4-4).

Table 4-4: Association between gender and cause of injury

	TBI	Infection	Totals
Male	13	1	14
Female	0	3	3
Totals	13	4	17

Fisher exact, one-tailed p=.006

The median time from injury to assessment was 2.8 month (range .8-7.1) post-injury, with 12 children having been injured three months or less previously (Figure 4-3).



Category boundaries x-x.99

Figure 4-3: Histogram of time since injury at assessment

4.4 Gross Motor Function Classification Scale (GMFCS)

As can be seen in Table 4-5, most children were ambulant (12) with five children more severely affected.

Table 4-2: Gross motor function classification system

GMFCS Level	Count	Cumulative Count
I	3	3
II	3	6
III	6	12
IV	3	15
V	2	17

Table 4-6: Aetiology per GMFCS level

Cause	GMFCS level I	GMFCS level II	GMFCS level III	GMFCS level IV	GMFCS level V	Row Totals
TBI	3	1	5	2	2	13
Infection/ stroke	0	2	1	1	0	4
All Groups	3	3	6	3	2	17

There were children whose ABI was attributable to either TBI or Infection/stroke spread across the levels.

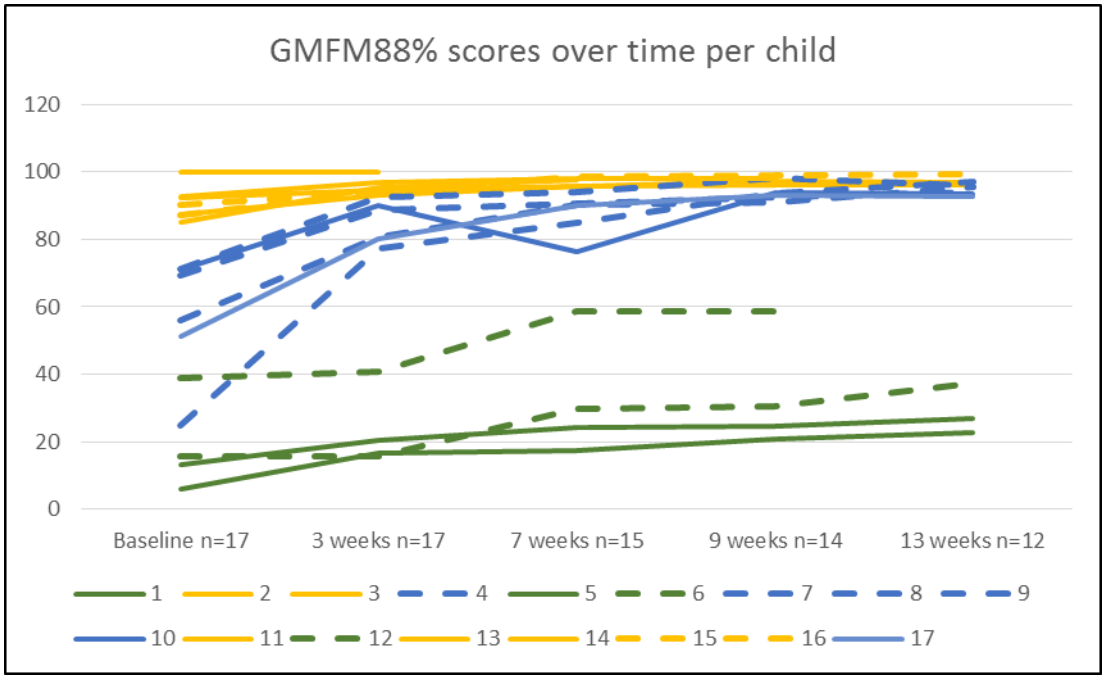
4.5 Gross Motor Function Measure (GMFM88)

GMFM88 scores at each time are presented below. One child, 11, showed no variance as his/her score was 100 at Baseline. One child had the week 7 and 9 data points missing, and one child had the Week 9 data point missing. The children received either intensive or intermittent treatment. At Baseline eight of the children were assigned for intensive therapy and nine for intermittent. After Week 3, a child (15) on GMFCS level one in the intensive group fell out of the study, leaving seven children this group. He had very little motor fallout according to his GMFM88 Total % score at Baseline (98%).

Table 4-7: The GMFM88 % scores over time

	GMFCS	Age	Intervention group	Baseline n	Week 3 n=17	Week 7 n=15	Week 9 n=14	Week13 =12	Progress Group
1	4	105m	intensive	13.4	20.6	24.1	24.5	26.9	C
2	2	156m	intensive	87.2	93.2	95.8	97.4	97.1	A
3	1	43m	intensive	92.2	94.6	95.7	96	96.3	A
4	2	53m	intermitter	71.1	92.6	94.1	98.4	95.8	B
5	5	28m	intensive	5.9	16.6	17.2	20.8	22.8	C
6	5	72m	intermitter	15.5	15.5	29.8	30.5	37.5	C
7	3	107m	intermitter	69.4	88.6	90.6	92.7	94.1	B
8	3	84m	intermitter	56.2	80.9	90.3	91.1	95.4	B
9	4	155m	intermitter	24.9	77.2	84.9	93.7	97.1	B
10	3	46m	intensive	71	90.1	76.5	94	93.5	B
11	1	148m	intensive	100	100				A
12	4	138m	intermitter	39.1	40.7	58.5	58.5*		C
13	2	119m	intensive	92.7	97	98.1	97.9		A
14	3	115m	intensive	85.1	95.2	97.8			A
15	1	162m	intermitter	90.1	94.2				A
16	3	156m	intermitter	87.2	93.9	98.6	98.9	99.4	A
17	3	26m	intermitter	51.3	80.2	90.1	93.2	92.8	B

*Green indicates lower and red higher scores. * Little parental involvement and absconded. Group A= high percentage score baseline score, Group B= Baseline score of 50-70%, Group C=baseline scores of 40% or below.*



Solid line = Intensive programme, Dotted line = intermittent programme. Group A = Orange, Group B=Blue, Group C = Green (see below).

Figure 4-4 Change in GMFM88T % score over time for each child

There appeared to be three groups, one of which started with a high percentage score and maintained this up to Week 9 (Group A, n=7). The second group, B (n=6), started with a score of 50-70% (with one exception), made rapid improvement up to Week 3 and then showed sustained but slower improvement until Week 9, finally attaining approximately 100%. The third group, C (n=4), who started with scores of 40% or below, demonstrated far slower progress and still had a severe functional deficit by Week 13 (or Week 9 as in one case with missing data).

All the children in the C group had been classified on Level IV and V of the GMFCS (Table 4-8).

Table 4-8: Progress Group tabulated per GMFCS level

GMFCS Level	Progress Group A	Progress Group B	Progress Group C	Row Totals
I	3	0	0	3
II	2	1	0	3
III	2	3	0	5
IV	0	0	2	2
V	0	0	2	2
Totals	7	4	4	15

The scores at each time point were significantly ($p<.05$) and highly correlated ($rho>.75$) with all other time points, with the Week 1 and 3 showing the highest correlation ($rho=.966$) and 3 and 13 showing the lowest (0.727).

Table 4-9: Correlation matrix of GMFM depicting Spearman's rank order correlation values between the different time points.

	N	Baseline	Week 3	Week 7	Week 9	Week 13
Baseline	17	1.000	0.966	0.925	0.886	0.748
3 weeks	17		1.000	0.925	0.890	0.727
7 weeks	15			1.000	0.890	0.832
9 weeks	14				1.000	0.832

All significant at the p<.05 level.

Regression analysis, with one outlier removed who's predicted score was more than 2 SD different form the observed score indicated that the GMFM88% score at Baseline accounted

for 86% of the variance in the Week 9 score (chosen as there was less attrition at this time point). The predicted score at Week 9 increased by .94 for each additional point on the Baseline score.

Table 4-10: Regression summary for GMFM88% score at Week 9 (dependent variable) and Baseline score (independent variable)

	b*	Std.Err. of b*	b	Std.Err. of b	t(11)	p-value
Intercept			22.23	7.047	3.154	0.009
Baseline GMFM88%	0.934	0.108	0.94	0.108	8.650	0.000

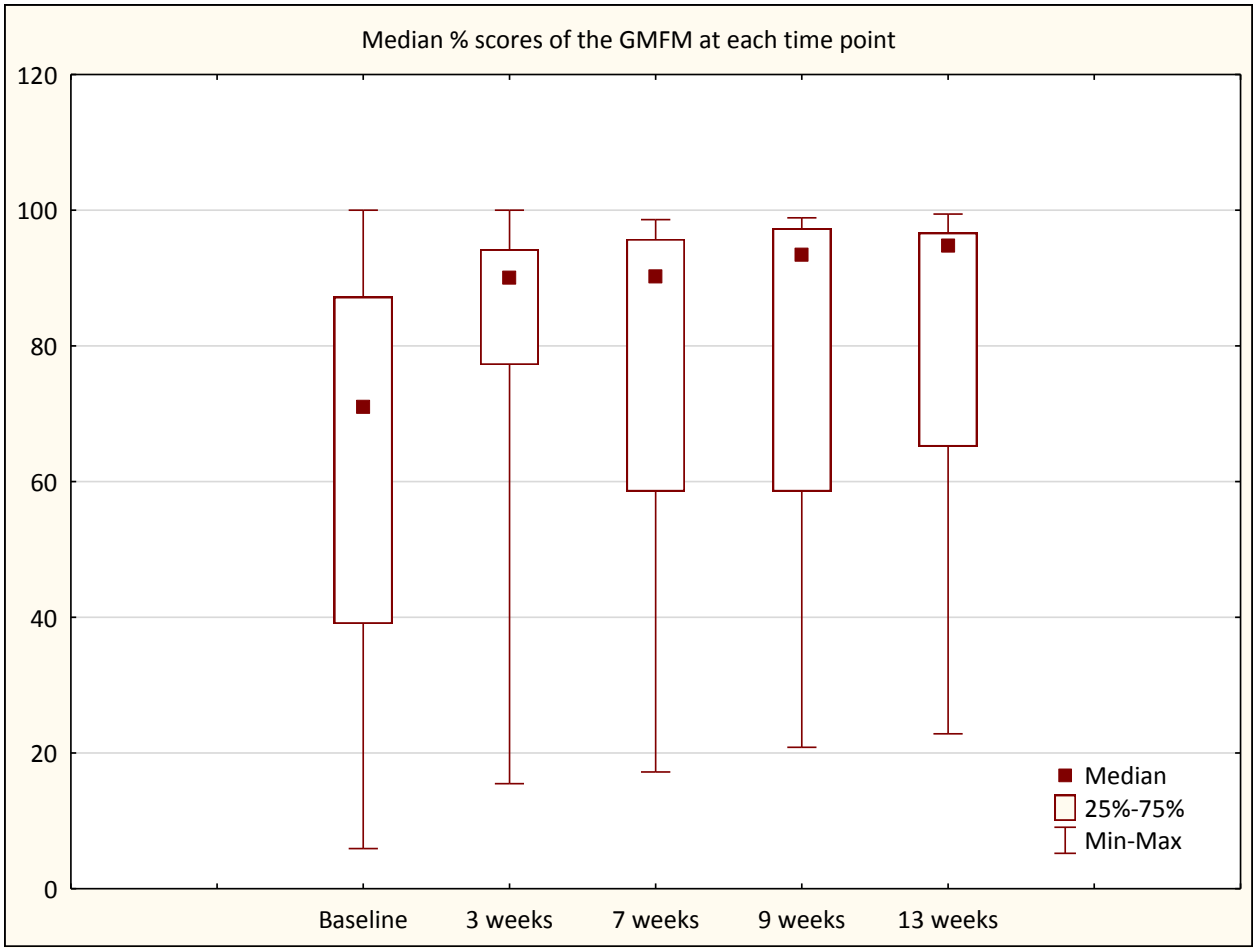
N=13, Adjusted R^2=.860, F (1,11)=74.816 p

Table 4-3: Predicted Week 9 GMFM88% scores based on Baseline scores

	b-Weight	Baseline score	b-Weight	b-Weight	Baseline score	b-Weight
	0.94	20.0	18.7	0.94	70.0	65.6
Intercept			22.2			22.2
Predicted			41.0			87.8
-95.0%CL			29.5			80.2
+95.0%CL			52.4			95.5

Based on this analysis, a child with a Baseline score of 20 is predicted to achieve a Week 9 score of 41 (CIs 29.5-52.4) and a child with 70 at Baseline should achieve 87.8 (CIs 80.2-95.5)

There were 14 participants with scores up to 9 weeks. The median values were compared using Friedman's ANOVA and a significant difference was found across the four time points. (ANOVA Chi Sqr. (df = 3) = 39.1 p <.001). At Week 13, the number of participants had dropped to 12, but there was still a significant difference between the time points (ANOVA Chi Sqr. (df = 4) = 44.9, p <.001)



ANOVA Chi Sqr. (N = 12, df = 4) = 44.9 p <0.001

Figure 4-5: Boxplot of GMFM scores at each time point

The sign test indicated that, as time progressed, the proportion of participants who showed improvement increased significantly, apart from the improvement between Week 9 and 13. Although 66% had a higher score at Week 13 than Week 9 this proportion was not significantly higher (p=.386) (Table 4-13).

Table 4-12: Sign test and effect size comparing GMFM88 scores at each time point with the next time point

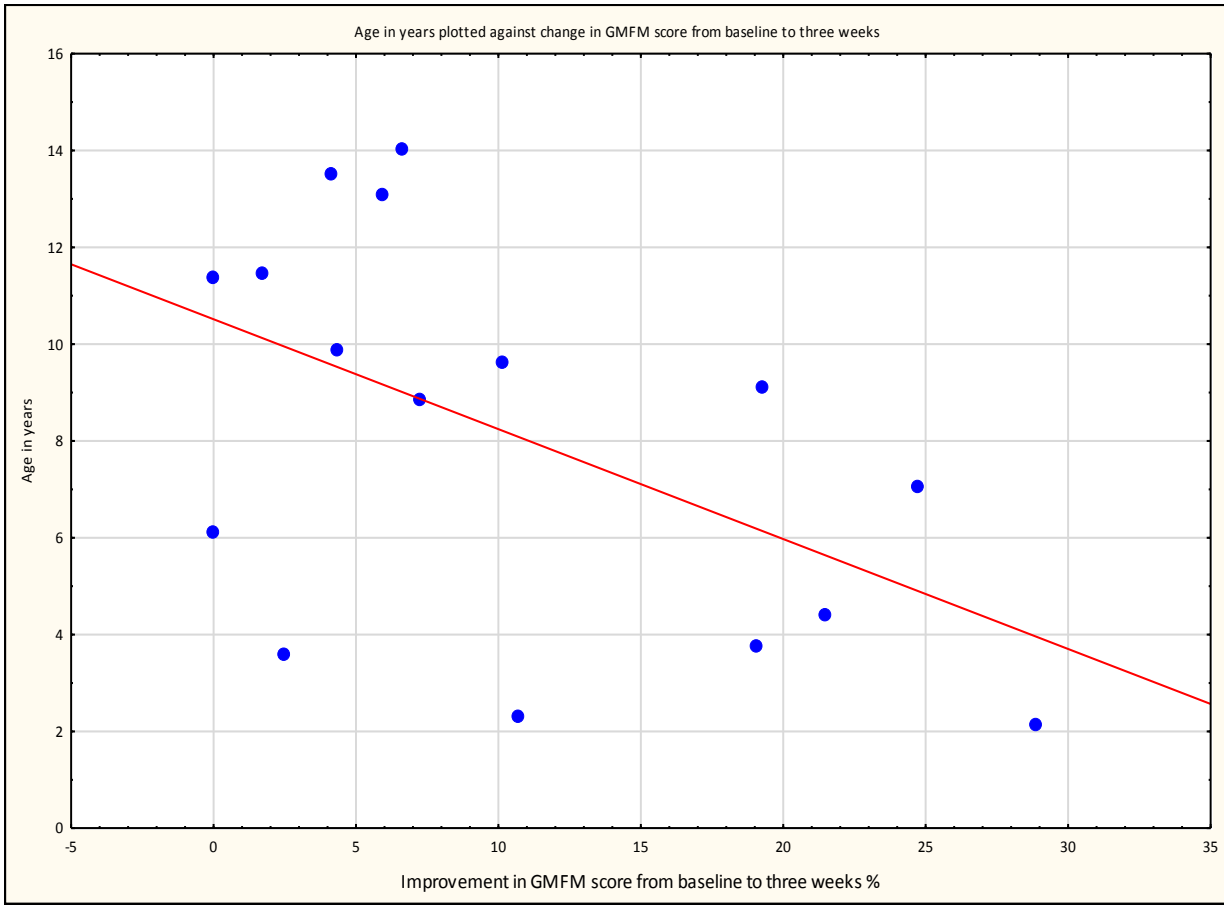
Time point	Compared to:	N scores	No. of non-ties	Percent greater at 2nd time point	Z	p-value	Effect size	
Baseline	Weeks 3	17	15	100.0	3.615	p<.001	0.639	Medium
	Weeks 7	15	15	100.0	3.615	p<.001	0.660	Medium
	Weeks 9	14	14	100.0	3.474	0.001	0.634	Medium
	Weeks 13	12	12	100.0	3.175	0.001	0.648	Medium
Weeks 3	Weeks 7	15	15	93.3	3.098	0.002	0.531	Medium
	Weeks 9	14	14	100.0	3.474	0.001	0.634	Medium
	Weeks 13	12	12	100.0	3.175	0.001	0.648	Medium
Week 7	Weeks 9	14	13	92.3	2.774	0.006	0.524	Medium
	Week 13	12	12	100.0	3.175	0.001	0.648	Medium
Week 9	Week 13	12	12	66.7	0.866	0.386	0.177	No effect

The Baseline score was correlated with the 13 Week score (n=12, rho=.748, p=.005).

4.6 Association between change in GMFM88 % scores and other factors

There was a strong correlation between the Baseline and Week 3 GMFM88 % score and the change in score was used as the outcome variable to identify which factors were related to improvement. The association between the change in GMFM88 scores from Baseline to Week 3 and the ages of the children, the time since injury and their initial GMFM88 Baseline score were examined using bivariate analysis as the sample size was too small to support multivariate analysis.

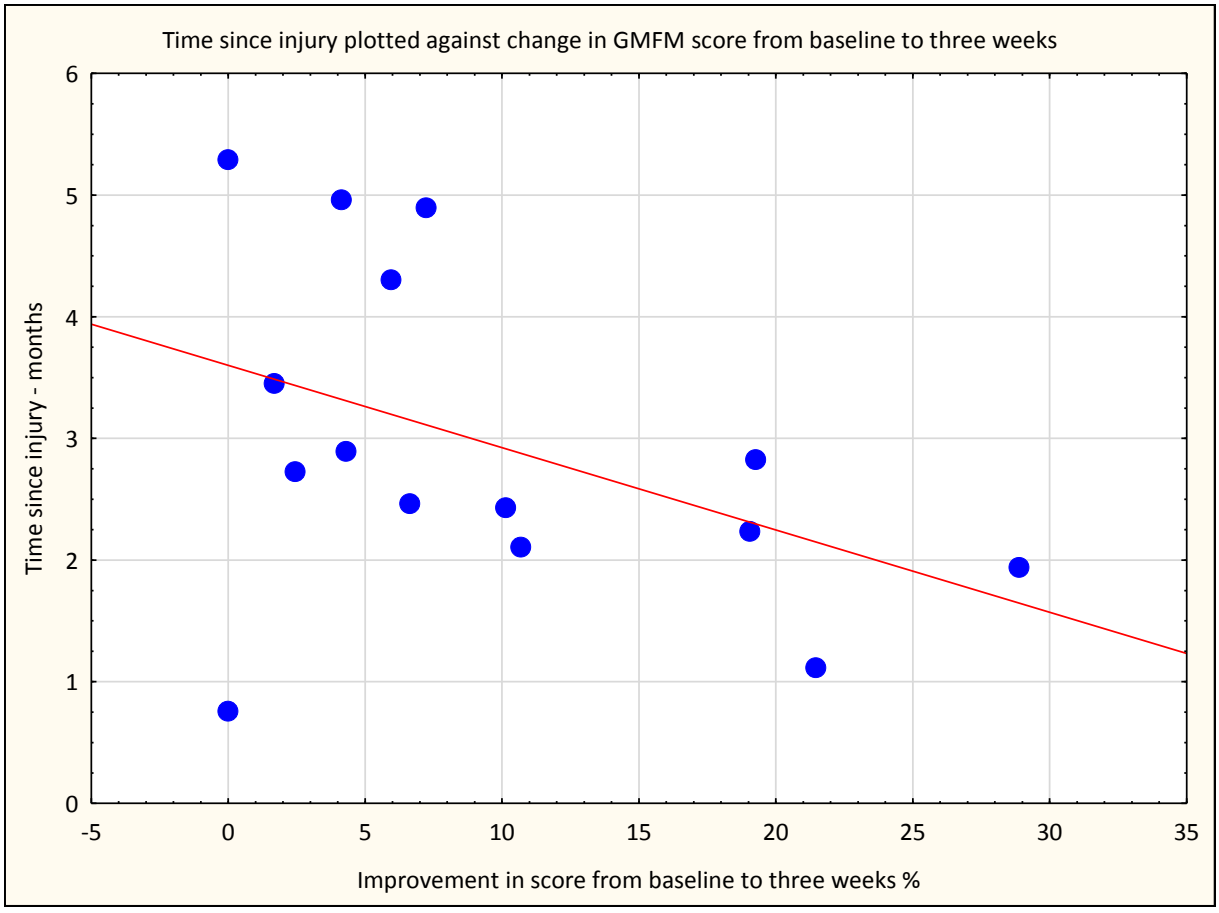
The rank correlation between the age of the children and the change in GMFM88 score approached significance and was negative, with older children showing the least improvement (Figure 4-6).



N=15, one outlier removed. Rho=-48, p=0.072

Figure 4-6: Age in years plotted against change in GMFM88% score from Baseline to three weeks

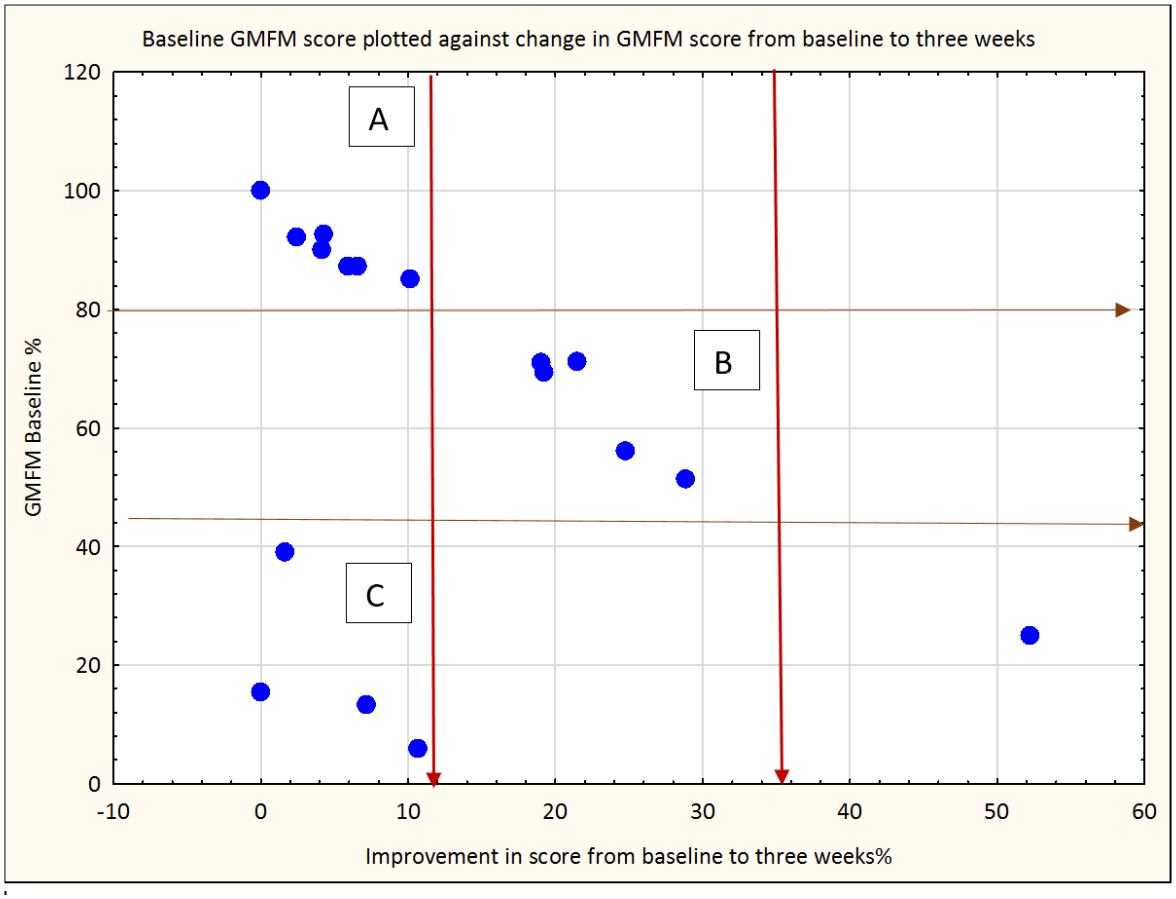
The correlation between the time since injury and the amount of improvement from Baseline to three weeks is depicted in Figure 4-7 once two outliers have been removed. The correlation was negative and approached significance (rho = -0.47, *p* = 0.081) which might indicate in a larger sample that the longer the time since injury, the smaller the improvement made in this time. Kruskall-Wallis ANOVA by ranks indicated that there was no difference in the time since injury between the different GMCS levels (EQ-5D-Y (4, N= 17) =2.61 p =.625)



N=15, 2 outliers removed, rho= -0.47, p = 0.081

Figure 4-7: Scatterplot of improvement in GMFM88 score from Baseline to Week 3 plotted against the time since injury

As was evident in Figure 4-7, there appeared to be three different patterns of improvement. This was further demonstrated in the scatterplot below in Figure 4-8, where both the high performing and low performing children at Baseline, showed 12 or less points of improvement, compared to the second group, with initial scores of between 50-75% who improved about 20 points or more in the first three weeks after treatment was initiated. The correlation between Baseline score and change in score was not significant (rho =-0.39, *p*=0.164) due to the small improvement being seen in children with the highest and the lowest functioning.



N=17, Rho *=-.39, p=.164*

Figure 4-8: Baseline GMFM88 Score plotted against change in GMFM88 score from Baseline to Week 3.

There was no significant difference in the rank ordering of the change in GMFM88 scores between males and females (*p*=0.753), those who had had a motor vehicle accident (*p*=0.777) and those that had intensive or intermittent physiotherapy (*p*=0.290). (Table 4-14).

Table 4-13: Comparison of the rank ordering of the change in GMFM88 between Baseline and Week 3 for gender, cause, and type of intervention

	Rank Sum	Rank Sum	U	Z	p-value	Valid N	Valid N
Gender						Male	Female
	123.0	30.0	18.0	-0.32	0.753	14	3
Cause						Motor Vehicle Accident	Other
	120.0	33.0	23.0	0.28	0.777	13	4
Intervention						Intermittent	Intensive
	60.5	92.5	24.5	-1.06	0.290	8	9

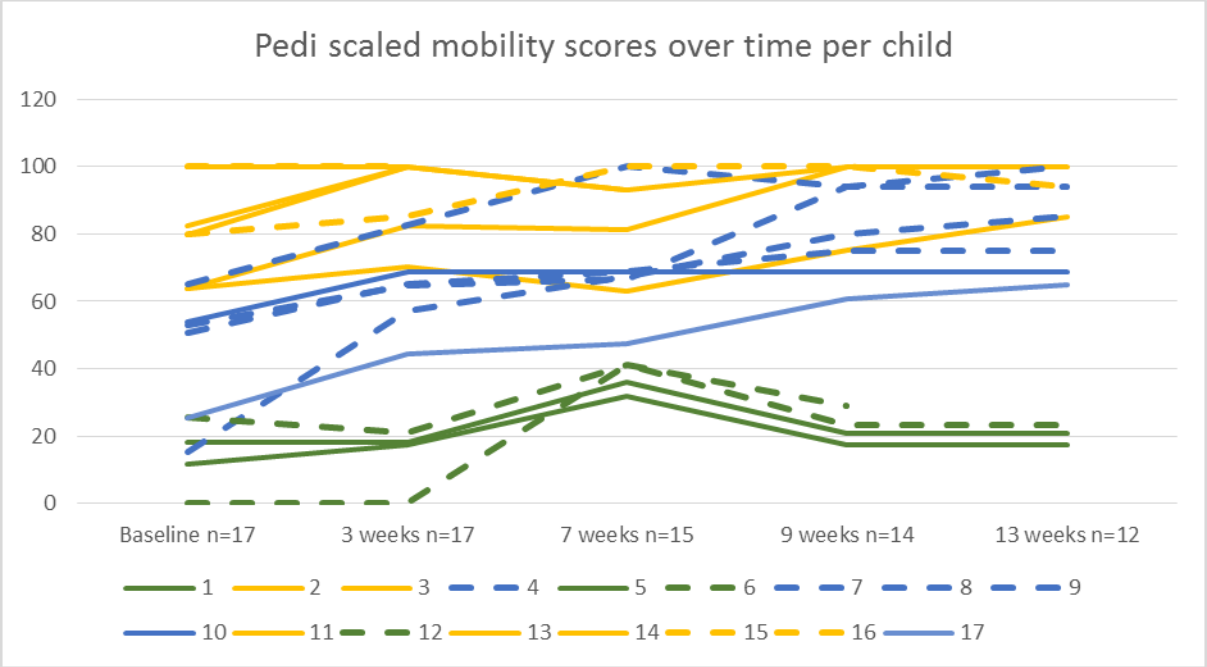
4.7 Pediatric Evaluation of Disability Inventory (PEDI)

The PEDI raw scores are given in Appendix 8. The median score on the PEDI Mobility scale at Baseline was 53.9 (0-100) and this rose to 80.2 (17.4-100) at Week 13 (Table 4-14).

Table 4-4: PEDI Mobility Scaled score over time per participant

		Baseline n=17	Week 3 n=17	Week 7 n=15	Week 9 n=14	Week13 n=12
	Intervention group					
1	intensive	18.2	18.2	36	20.9	20.9
2	intensive	63.9	82.5	81.4	100	100
3	intensive	63.9	70.1	63.2	75.2	85.2
4	intermittent	65	82.5	100	94.2	100
5	intensive	11.8	17.4	31.9	17.4	17.4
6	intermittent	0	0	41.2	23.3	23.3
7	intermittent	53.1	64.6	66.8	94.2	94.2
8	intermittent	50.5	65	69.1	75.2	75.2
9	intermittent	15.2	57.3	67.6	79.8	85.2
10	intensive	53.9	68.7	68.7	68.7	68.7
11	intensive	100	100			
12	intermittent	25.4	20.9	41.2	29	
13	intensive	82.5	100	93	100	
14	intensive	79.8	100	93		
15	intermittent	100	100			
16	intermittent	79.8	85.2	100	100	94.2
17	intermittent	25.4	44.3	47.5	60.9	65
		53.9 (0-100	68.7 (0-8.7)	74.25 (17.4-100)	75.2 (17.4-100)	80.2 (17.4-100)

Green indicates lower and red higher scores



Solid line = Intensive programme, Dotted line = intermittent programme. Group A = Orange, Group B=Blue, Group C = Green as defined by GMFM88 performance.

Figure 4-9 : Change in PEDI Mobility Scaled Score over time

The three groups identified in the plot of the GMFM88 % show a similar progression in Figure 4-9, with most in A Group starting with high scores and reaching over 80% by Week 13, B group showing consistent and greater improvement and the C group starting and remaining with lower scores throughout the course of the study.

The Friedman ANOVA indicated that the rank ordering of the median was significantly different across the time points (ANOVA Chi Sqr. (N = 11, df = 4) = 38.7 p =<.001). The sign test indicated that the Baseline and Week 3 measures were significantly different to all other measures with a medium effect size, but that the proportion of children scoring higher was no different between the Seven and Nine Week scores Table (4-15).

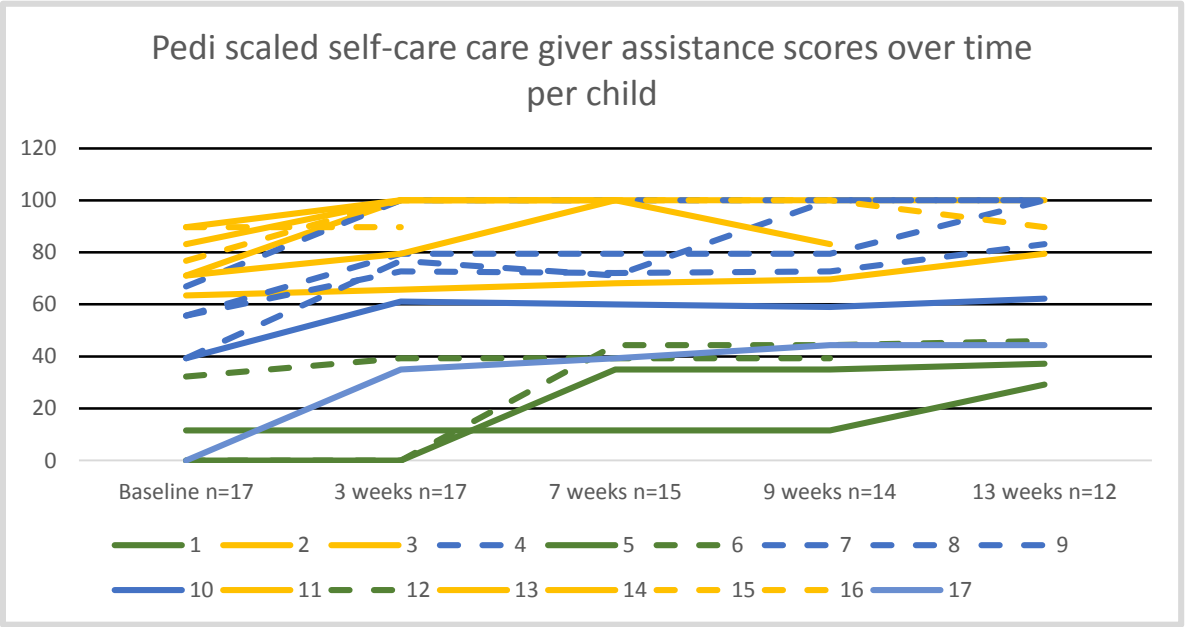
Table 4-5: Comparison of PEDI Mobility scores across time points

Time point	Compared to:	N scores	No. of non-ties	Percent greater at 2nd time point	Z	p-value	Effect size	
Baseline	3 weeks	17	13	92.3	2.774	0.006	0.49	Medium
	7 weeks	15	14	100.0	3.474	0.001	0.634	Medium
	9 weeks	14	14	100.0	3.474	0.001	0.634	Medium
	13 weeks	12	12	100.0	3.175	0.001	0.648	Medium
3 weeks	7 weeks	15	11	100.0	3.015	0.003	0.517	Medium
	9 weeks	14	11	100.0	3.015	0.003	0.55	Medium
	13 weeks	12	10	100.0	2.846	0.004	0.581	Medium
7 weeks	9 weeks	14	5	80.0	0.894	0.371	0.169	No effect
	13 weeks	12	3	100.0	1.155	0.248	0.236	Small
9 weeks	13 weeks	12	5	80.0	0.894	0.371	0.182	No effect

The median score on the PEDI self-care with care-giver assistance was 55.7 (0-100) and this increased to 81.35 (29.2-100) at 12 weeks (Table 4-16). The PEDI Self Care with care-giver assistance reached a ceiling score of 100 in four of the children.

Table 4-6: PEDI Self Care Scaled with caregiver assistance score over time per participant

	Baseline n=17	3 weeks n=17	7 weeks n=15	9 weeks n=14	12 weeks n=12
1	0	0	35	35	37.2
2	71.1	100	100	100	100
3	63.4	65.7	68.1	69.6	79.5
4	66.9	100	100	100	100
5	11.6	11.6	11.6	11.6	29.2
6	0	0	44.4	44.4	45.9
7	55.7	79.5	79.5	79.5	100
8	55.7	72.7	72.1	72.7	83.2
9	39.3	76.7	71.1	100	100
10	39.3	61.1	60	59	62.2
11	83.2	100			
12	32.3	39.3	39.3	39.3	
13	71.1	79.5	100	83.2	
14	89.7	100	100		
15	89.7	89.7			
16	76.7	100	100	100	89.7
17	0	35	39.3	44.4	44.4
	55.7 (0-100)	76.7 (0-100)	71.6 (11.6-100)	71.15 (11.6-100)	81.35 (29.2-100)



n=17, Solid line = Intensive programme, Dotted line = intermittent programme. Group A = Orange, Group B=Blue, Group C = Green as defined by GMFM88 performance.

Figure 4-10: The Pedi scaled self-care with caregiver assistance scores over time per child.

The change over time in the self-care dimension did not differentiate the same groups as clearly as the GMFM88 or the mobility dimension. Whereas the Group C members remained the lowest scoring overall, some of the Group A children perform at a lower rate than in the GMFM88, as did some of the Group B children.

Friedman's Anova indicated that there was a significant difference between the median ranking of the PEDI Self-care scaled score at the different time points (ANOVA Chi Sqr. N=11, df=4, 30.33, p <.001).

The pattern of improvement was slightly different to the mobility domain as the effect size was medium from Baseline to all the other time points but only small to no effect between the other time points (Table 4-17).

Table 4-77: Sign test comparing Self-care with Care-giver assistance Scaled Scores at each time point

Time point	Compared to:	N scores	No. of non-ties	Percent greater at 2nd time point	Z	p-value	Effect size	
Baseline	Week 3	17	13	100.0	3.328	0.001	0.588	Medium
	Week 7	15	13	100.0	3.328	0.001	0.608	Medium
	Week 9	14	13	100.0	3.328	0.001	0.608	Medium
	Week 13	12	12	100.0	3.175	0.001	0.648	Medium
3 weeks	Week 7	15	7	71.4	0.756	0.450	0.13	No effect
	Week 9	14	7	85.7	1.512	0.131	0.276	Small
	Week 13	12	10	90.0	2.214	0.027	0.452	Small
7 weeks	Week 9	14	5	80.0	0.894	0.371	0.169	No effect
	Week 13	3	9	88.9	2.000	0.046	0.408	Small
9 weeks	Week 13	12	8	12.5	1.768	0.077	0.361	Small

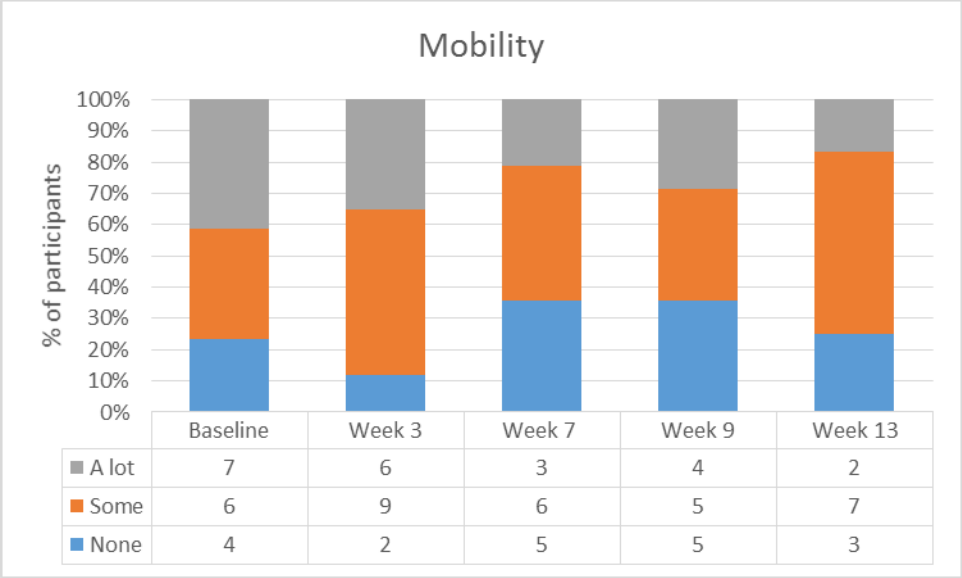
A Friedman's Anova was conducted to test for change over time in each of the PEDI dimensions from Baseline to Week 9. Results indicate a significant difference over time for each dimension. However, when testing to see where the greatest change occurred between time points employing the Sign test, significance was only consistently yielded between Week 1 and Week 3.

4.8 EQ-5D-Y proxy (Health related quality of life measurement for children)

The frequency of reported problems by dimension is presented below. There were a decreasing number of children on whom the caregivers reported over the different time points as several children did not attend for the last assessments.

Figure 4-11 no consistent trend in the "None" and "Some" dimension scores. The "A lot" showed a general decrease in trend over time. The "None" from Baseline to the second-time point decreases and then increases to remain approximately the same at the following two-time points. There is a greater proportion of respondents reporting that their child has "Some problems" at the Week 13time point.

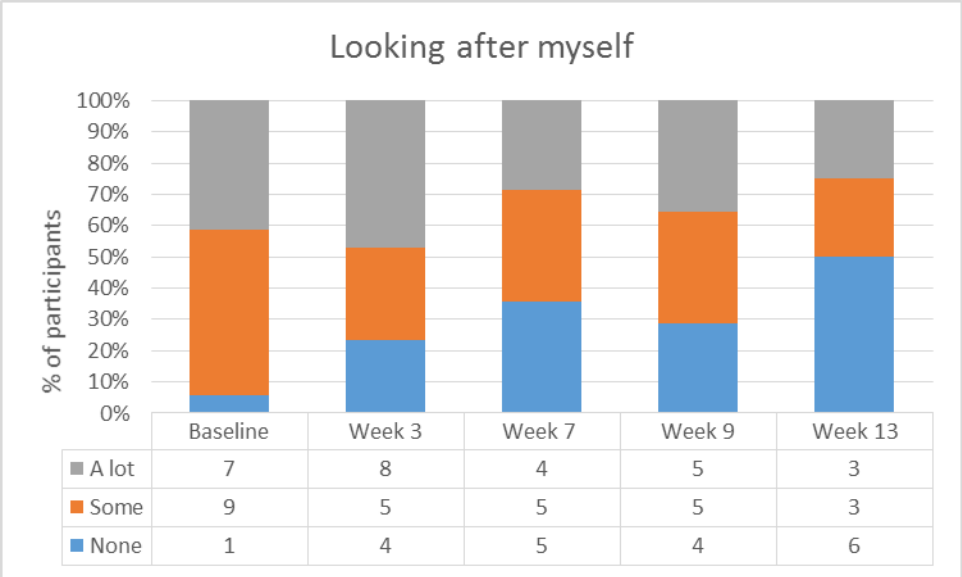
Figure 4-11: EQ-5D-Y mobility score at Week1 (Baseline), 3, 7, 9 and 13.



	Baseline	Week 3	Week 7	Week 9	Week 13
A lot	7	6	3	4	2
Some	6	9	6	5	7
None	4	2	5	5	3

The caregivers 12 (N=17) reported an improvement in their children's ability to look after themselves. A reduction is observed in the reported frequencies in the "A lot" category 9 (N=17) at Baseline reduced to 3 (N=12) at Week 13 (Figure 4-12) and a generally increasing proportion of "None" over the time periods (Figure 4-12).

Figure 4-12: EQ-5D-Y Looking after self- scores at Week1 (Baseline), 3, 7, 9 and 13.



	Baseline	Week 3	Week 7	Week 9	Week 13
A lot	7	8	4	5	3
Some	9	5	5	5	3
None	1	4	5	4	6

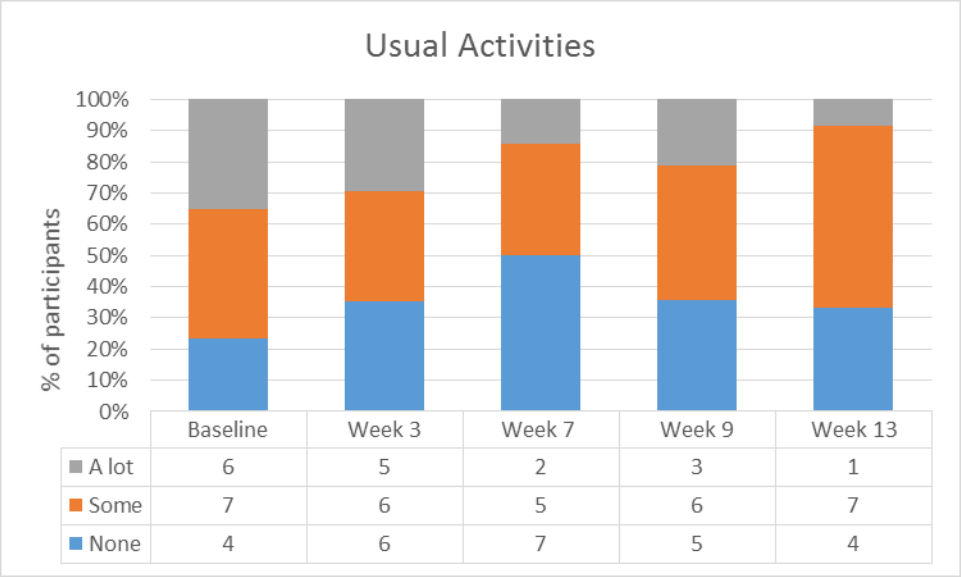
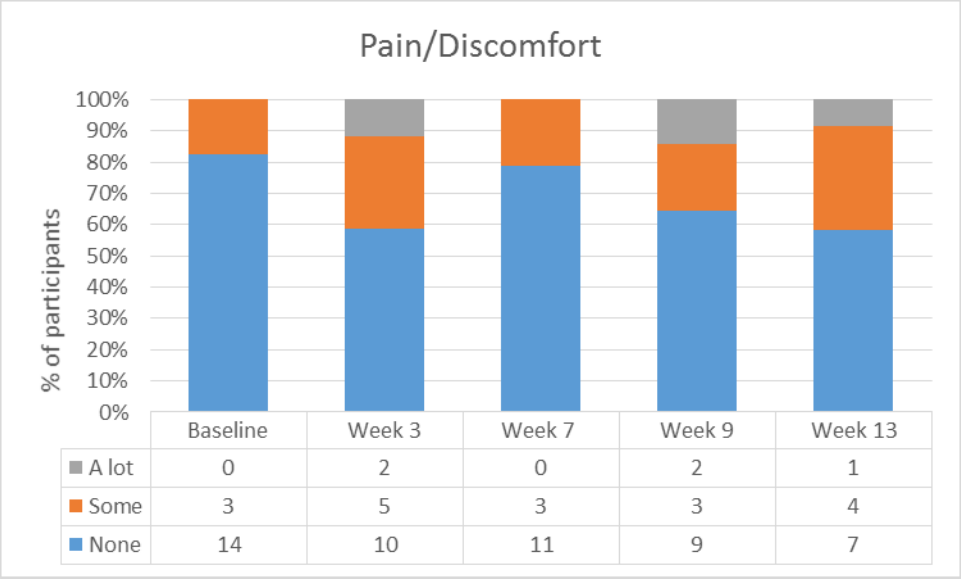


Figure 4-13: EQ-5D-Y Usual Activities Score at Week 1 (Baseline), 3, 7, 9 and 13.

Parents generally perceived that their children improved in their ability to perform usual activities (Figure 4-14). A downward trend is observed in the "A Lot" category. However, of those that attended the Week 13 assessment, a greater proportion reported "Some" problems than at other time points.

Figure 4-14: EQ-5D-Y Pain and Discomfort scores at Week1 (Baseline), 3, 7, 9 and 13.



At Baseline, the no caregiver reported that their child had “A lot” of pain and the majority reported “None”. However, this changed over the time points and the proportion reporting pain increased although the number with “Some” remained almost constant after Week 3.

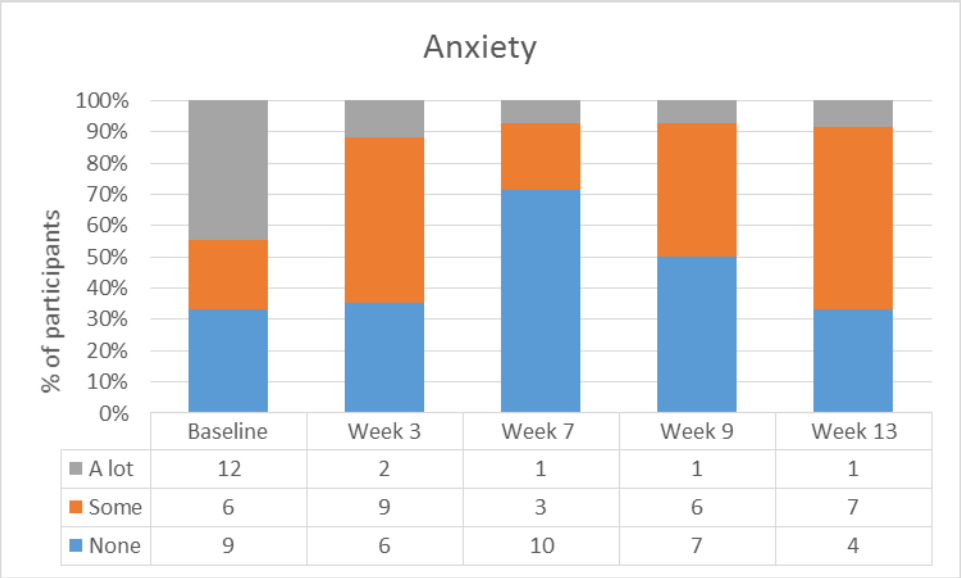


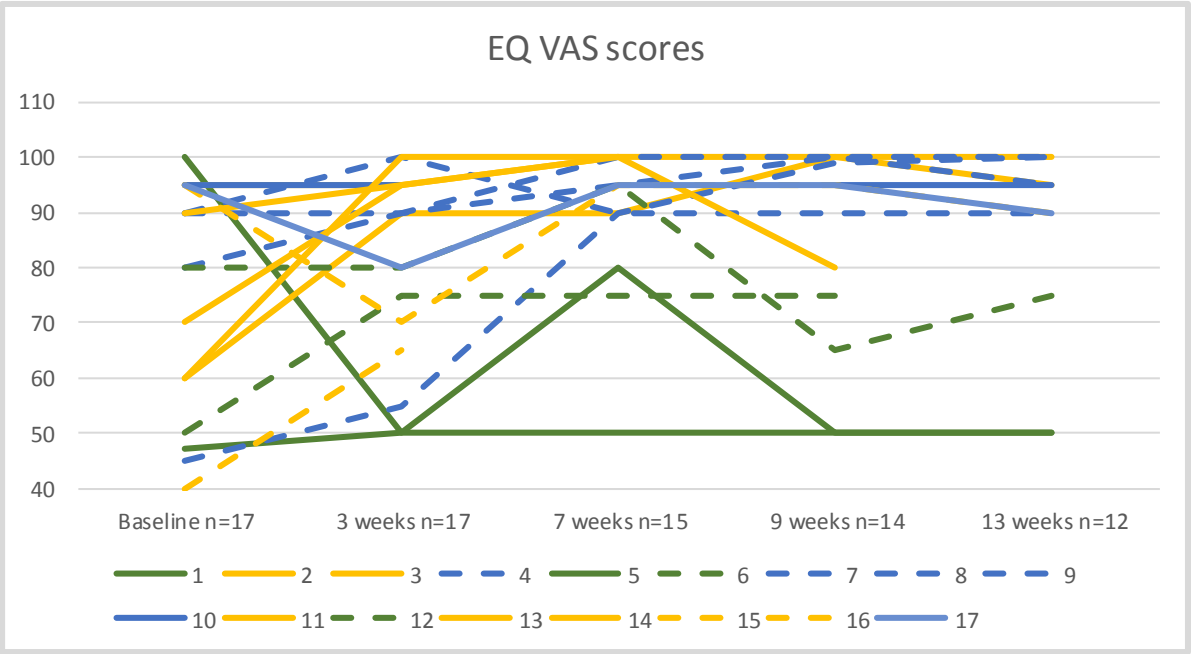
Figure 4-15: EQ-5D-Y5DY Anxiety Scores at Week 1 (Baseline), 3, 7, 9 and 13.

There was no consistent trend in the “None” and “Some” categories. A general decrease in trend is observed in the “A lot”. The caregivers 2 (N=17) reported “A lot” of anxiety at Baseline compared to 1 (N=12) in Week 13. However, 7 (N=12) reported anxiety as Some” at Week 13 (Figure 4-15).

Table 4-88: EQ Visual analogue scale scores across the time points.

ID number	Baseline n=17	Week 3 n=17	Week 7 n=15	Week 9 n=14	Week13 n=12
1	100	50	50	50	50
2	60	90	90	100	95
3	95	95	100	100	100
4	80	90	95	100	95
5	47	50	80	50	50
6	80	80	95	65	75
7	90	90	100	100	100
8	90	100	90	90	90
9	45	55	90	99	100
10	95	95	95	95	95
11	70	95			
12	50	75	75	75	
13	60	100	100	80	
14	90	95	100		
15	40	65			
16	95	70	95	95	90
17	95	80	95	95	90
Median (range)	80 (40-100)	90 (50-100)	95 (50-100)	95 (50-100)	92.5 (50-100)

Green indicates lower and red higher scores.



Solid line = Intensive programme, Dotted line = intermittent programme. Group A = Orange, Group B=Blue, Group C = Green as defined by GMFM88 performance.

Figure 4-16: Change in the Visual Analogue scale scores of the children as reported by their caregivers per child

The Friedman ANOVA indicated that there was no significant change across the different time points (ANOVA Chi Sqr. (N = 11, df = 4) = 8.80 p = .066). Although not correlated at Baseline, the GMFM88 was correlated with the VAS at Week 13 (n=12, rho=.655, p=.021).

4.9 Caregiver Strain Index

Thirteen caregivers responded to the CSI at Baseline, reducing to 10 at Week 13. Figure 4-17 indicates that the greatest cumulative cause of strain was a change in the former self of the child, followed closely by financial strain and work adjustments. In general, apart from Week 3, during which fewer stressors were identified, the numbers of positive responses remained approximately constant across the course of the study.

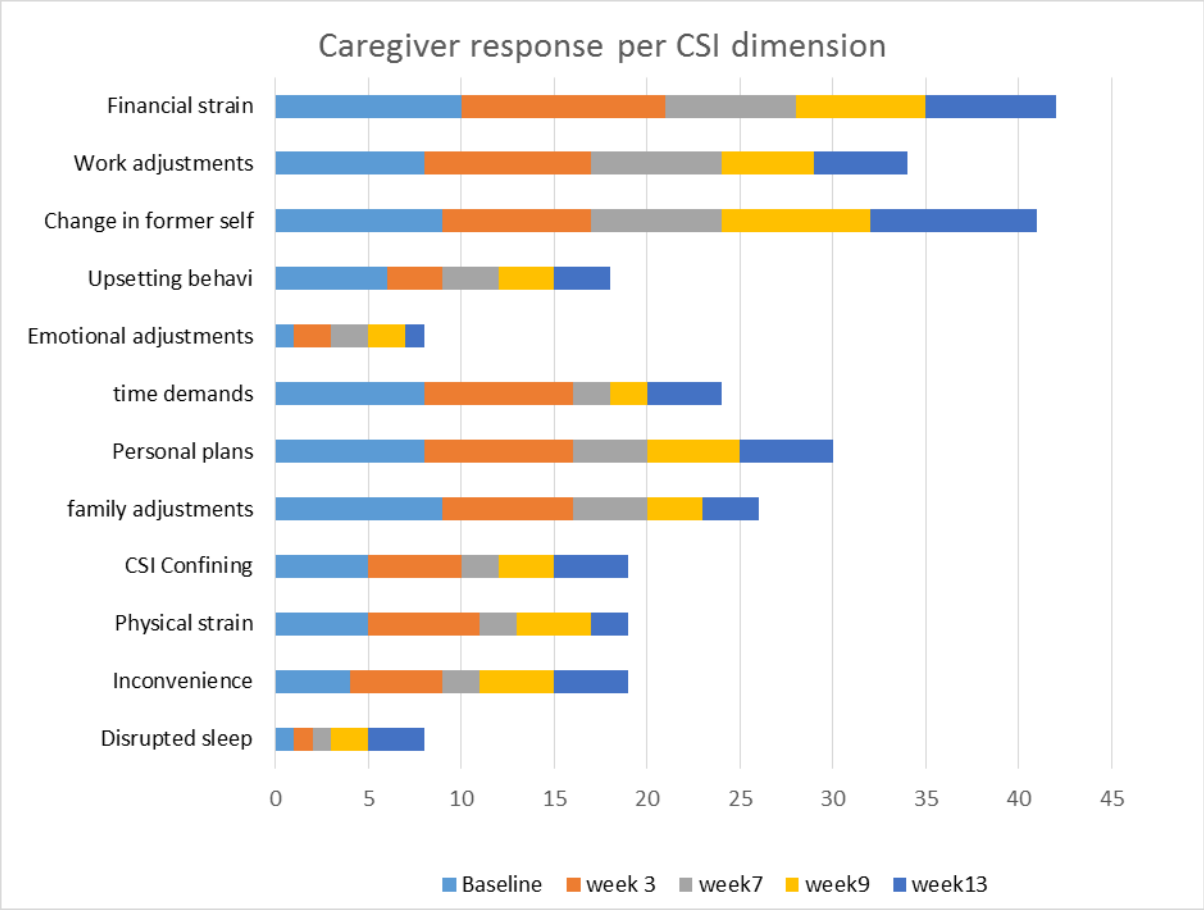


Figure 4-17: Cumulative number of positive responses to strain in each dimension of the CSI

The median CSI score reduced from seven to four from Baseline to Week 13 (Table 4-19). In general, the strain level reduced from Baseline in children in the A and B Group and remained high or increased in Group C children.

Table 4-9: Caregiver strain index scores across time-points

Child's ID Number	Progress Group	Baseline n=13	Week 3 n=13	Weeks 7 n=11	Weeks 9 n=11	Weeks 13 n=10
1	C	11	11	12	11	12
2	A	5	4	4	4	5
3	A					
4	B	1	4	1	4	2
5	C	9	10	4	11	12
6	C	4	4	3	3	6
7	B	11	12	9	8	3
8	B	1	1	5	2	2
9	B	3	3	3	2	2
10	B	7	7		1	1
11	A					
12	C					
13	A	8	6	3	3	
14	A					
15	A	11	11			
16	A	10	8	4	3	10
17	B	3	2			
Median (range)		7 (1-11)	6 (1-12)	4 (1-12)	3 (1-11)	4 (1-12)
Number reporting a high strain level*		7	6	2	3	3

*Green indicates lower and red higher scores. Higher scores reflect more strain. *Greater than seven.*

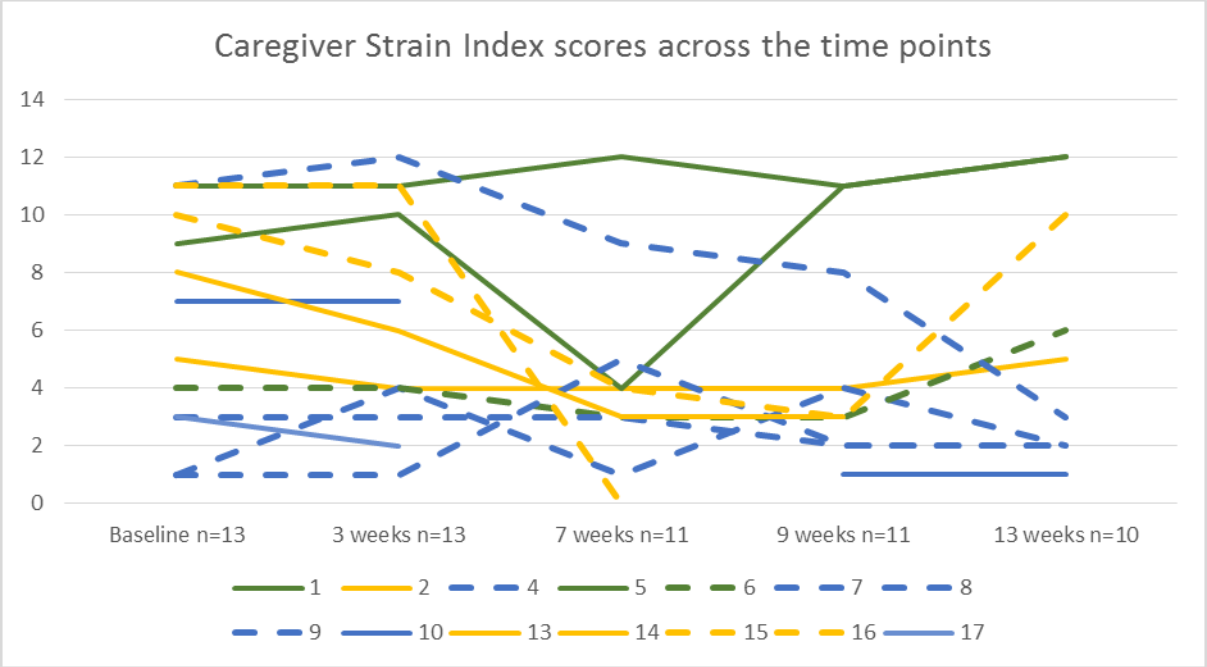


Figure 4-18: Change in reported Caregiver Strain over time

Friedman ANOVA Chi Sqr. (N = 10, df = 3) = 3.73, p= 0.29

To test for changes in the median CSI scores over time, Friedman's Anova of CSI scores was performed, and no significant differences between the different time points (p = .290) were found. Although not correlated at Baseline, the CSI was negatively correlated with the VAS at Week 13 (n=10, rho=-724, p=.018).655, p=.021).

4.10 Correlation between Baseline and Nine Week Scores

Spearman's correlation between the Baseline scores and the Week 9 scores was calculated as by Week 13, there was further attrition. All Baseline scores were significantly correlated with the outcome at Week 9, apart from the VAS at Baseline (Table 4-20). However, the Week 9 VAS was correlated with the Baseline and other scores.

Table 4-10: Correlation between Baseline and 9 Week scores on the functional measures

	PEDI Mobility Baseline	PEDI Self-care Baseline	VAS Baseline	GMFM Week 9	PEDI Mobility Week 9	PEDI Self-care Week 9	VAS Week 9
GMFM Baseline	0.937	0.851	-0.012	0.886	0.749	0.661	0.621
PEDI Mobility Baseline		0.919	-0.051	0.883	0.729	0.647	0.542
PEDI Self-care Baseline			-0.221	0.846	0.838	0.816	0.590
VAS Baseline				0.105	-0.145	-0.157	0.068
GMFM 9 weeks					0.852	0.834	0.679
PEDI Mobility 9 weeks						0.948	0.791
PEDI Self-care 9 weeks							0.733

N=14. All correlated at the p<.05 level, apart from VAS at Baseline

4.11 Narrative description of care-givers response to intervention

It was observed by the researcher and clinical physiotherapy staff at the Facility that caregivers appear to have inadequate information about their child's condition, the impact on the functional abilities of the child and prognosis. A common question raised by some of the caregivers were related to their child's prognosis to regain their premorbid status. Later within the study as the children regained more of their motor functional abilities, queries related to educational needs and behavioural changes emerged. However, this level of interest in their child's prognosis was only displayed by five of the caregivers. These caregivers asked questions regarding their child's prognosis, the role that they could play in assisting their child and the impact that their child's condition might have on schooling. The other 12 caregivers appeared impartial about their child's condition. They did not ask for any input or clarification and had poor compliance in following through on home programmes given to them.

4.12 Summary of findings

The demographic profile of most of the children indicated that they lived under situations of severe resource constraints. More than 70% of the children lived in low income households (income zero to less than R4000 per month) with one parent working. Just under half of the children lived with both parents. The study sample consisted of more boys than girls, with younger and older boy predominating. All the boys had a traumatic brain injury and the cause of injury in girls was non-traumatic and no correlation was found between amount of recovery in the first 3 weeks and cause of injury.

The median time for recruitment into the study was 2.8 months. No significant correlation was found between the amount of recovery up to three weeks post recruitment and time since injury, but a smaller improvement was found in those with a longer delay before recruitment and intervention (not significant). Treatment intensity did not appear to be associated with improvement and all the children showed a degree of improvement, no matter the intensity. The age of the child was not significantly correlated with the amount of improvement but there was a negative correlation which approached significance, implying that older children might show less improvement.

Three patterns of recovery were identified through plotting the GMFM88 scores, Group A included children with a high initial score who showed sustained but small improvement until reaching the ceiling score, B who started with lower scores and then improved considerably and C children who started with low scores and showed slower and smaller improvement. Thus, the most gains in GMFM88 were demonstrated by the children in Group B which included children on GMFCS levels III and IV. Possibly as a result of the bi-modal distribution of improvement, the Baseline GMFM88 scores was not significantly correlated with the change in score from Baseline to Week 3. Apart from no effect evident from Week 9 to 13, all the GMFM88 scores were significantly different from one time point to the next for all the children combined the effect size was medium (effect size of > 0.5). The Baseline score was significantly correlated with the Week 13 score.

The PEDI measured participation. A similar pattern in the children's PEDI mobility was found as seen in the GMFM88 over time, although the amount of change slowed down from Week 7 and the effect size was small to no effect from this time onwards. Eight children obtained 90% or higher. Although all the children improved in their ability to participate in domains of

self- care, the scores did not clearly differentiate the three progress groups and the rate of improvement in this dimension appeared to be different to the GMFM88 and the PEDI Mobility. The most change in the PEDI score was observed between Baseline and Week 13 (medium effect) and from Week 3 on there was a no to small effect from each time point to the others.

Although not subject to statistical analysis, the EQ-5D-Y indicated that from Baseline to Week 13, there was a decrease in the proportion of children with a lot of problems with Mobility, an increase in the proportion with no problems with Looking after Myself and a decrease in the number who had a lot of problems with Usual Activities and a corresponding increase in the number with some problems. The proportion reported to have no Pain/Discomfort decreased and there was an increase in those reported to have some "Worried, Sad or Unhappy". The reported child's VAS was not different over the course of the study.

Caregiver stress reduced over time, but not significantly as several care-givers reported increased stress at Week 13, included the caregivers of three of the children in Group C.

All Baseline measures were significantly correlated with each other and with the Week 9 score, apart from the VAS at Baseline. Although not correlated at Baseline the EQ-5D-Y VAS was correlated with the GMFM88 and the CSI at Week 13.

Chapter 5. Discussion

5.1 Introduction

The primary aims of the study were to identify patterns of improvement and to establish what factors were predictive of change in the short term. Three distinct groups of children emerged regarding the relearning of motor skills, whereas the patterns of self-care improvement were less linear and did not distinguish as much between children. Age of the child, age at injury, cause of injury, gender and intervention were not found to be related to the amount of motor improvement in the first three weeks. All Baseline functional measures were correlated with Week 9 outcome, apart from the initial VAS score.

The sample size of 17 was too small to allow for generalisation of the findings, outside of the Facility in which the study took place. It would have been preferable to extend the recruitment period, but this was not feasible within the time frames prescribed for the post-graduate degree. In addition, there was increasing attrition and by Week 13, only 12 were still attending. This might have been due to the children reaching their pre-injury potential as four of the five had attained a score higher than 94% on the GMFM88 at their last attendance and were classified in Group A. The 5th child was in Group C and the final score at Week 9 for this child was only 59%, but in this case, a lack of parental involvement was obvious. The final scores are therefore biased against the higher achieving children and are more representative of Groups B and C.

The results are discussed in detail below.

5.2 Contextual (environmental) factors, including care-giver attitudes and strain

The demographic representation of the study participants was not a surprise, as the mission of the research site Facility is to cater predominantly for children coming from low socioeconomic and resource poor communities [227]. In 14 of the households, caregivers relied on care-dependency grants to supplement low income jobs to support their families and in eight households this was their only source of income. The type of housing participants live in might also reflect their socioeconomic status. Apart from two families, all lived in either informal housing (n=11) or low-cost housing (n=5). This economic situation of the study population is similar to the wider population of South Africa as reported in the

2011 South African census [53, 228]. A census done in 2011 on the South African population reported 58% of the South African population living in poverty.

Any viable model of service provision employed needs to take cognisance of the limited financial and other resources of the parents, which may impact on treatment adherence and compliance. Although the attendance was regular at the scheduled assessments, clinical therapists reported that some caregivers did not participate in the rehabilitation process as agreed on entry in the study. The clinical staff based their assumptions on poor attendance of caregiver training sessions, visits to the Facility, caregiver attitude during caregiver therapist interactions, and poor follow through with home programmes given.

The caregivers did receive transport funding which might have improved compliance and attendance at scheduled assessments, but in the absence of such funding, poor socioeconomic circumstances might be a contributing factor to poor participation in caregiver training sessions, for several reasons, including having to take time off from work to attend the given appointments [55]. This might have been a challenge for those caregivers who are dependent on their income to support their families. Caregivers taking part in the study who worked (11 out of the 17) were mostly employed on a part time or casual basis (7 out of the 11). The concept of no work, no pay might have applied to them [229]. In a Zambian qualitative study by Khondewe et al. (2007), which involved ten caregivers of stroke patients from similar socioeconomic background, concerns expressed by the caregivers reported that the time required to care for the stroke patients placed their job security at risk [229] .

Poor attendance at rehabilitation can be due to lack of support structures available to caregivers in the care of siblings of the injured child [225]. In the current study, the role of primary caregiving fell mostly on the mothers of the children, most of whom had siblings. There were only three fathers that participated in the study. Having a child with a disability, in addition to existing care of a disabled elderly family member without family support, could possibly have increased the burden of care experienced by one caregiver [230, 231]. Not having support from other family members might impact on caregiver burden and consequently have an adverse impact on recovery [168]. The physical demands related to the care of one child, who had a severe ABI, might have led to an increase in the relevant caregiver's need for support [11, 232]. The caregiver of this child attended all the study

follow up appointments, thus no data is missing for this child. However, the therapy staff reported this caregiver's participation in therapy sessions as poor. Caregiver training sessions were not attended, and home programmes were poorly followed through. In addition to the possible impact on treatment compliance, the following factors were reported by the study caregivers as causes of caregiver strain. The impact of financial constraints and the effect on employment adjustments of caring for a child with ABI were highlighted as being among the major causes of caregiver stress, as were time demands and the need for family adjustments.

The need for further caregiver education was evident as it appeared that caregivers did not fully grasp information given to them, as reported elsewhere [233]. On the other hand, they might not have been receptive to the input given to them at the time, because of possible anxiety they experienced related to their child's survival [234]. The lack of engagement in therapy of some of the caregivers might have been due to multiple reasons. The traditional medical belief that recovery of their child lies within the hands of the rehabilitation practitioner might have prevailed [235]. Cultural differences between the caregiver and the rehabilitation therapist in what a caregiver relationship should entail could also have contributed [233]. If the caregiver's idea of care differed considerably from that of the service providers, they might not see themselves taking on the role expected by the therapist [236]. They might have felt disempowered about the role that they could play or their socio-economic situation impacted on their ability to be involved in their child's rehabilitation [232].

Although, the focus of a physiotherapy intervention is to facilitate optimal motor recovery of the child, this cannot be achieved or occur in isolation. It is important to note that the CSI scores do not solely reflect the motor performance of the children, but also reports on the high levels of strain reported by caregivers of children in Group A, who had more severe behavioural problems. Consideration of the overall needs of the child and caregiver is thus warranted. Rehabilitation should adopt a bio-psychosocial approach based on the International Classification of Function and Disability framework [72], [71], taking all aspects of the child internal and external into account during intervention. Consideration of the overall needs of the child and caregiver is thus warranted. Physiotherapy should be provided as part of an inter-sectoral multidisciplinary team approach [70]. Psychological and

social work support must be sought when indicated. Hence, the physiotherapist has a role to play in the early identification of care support needs of caregivers. Cultural, religious, level of education, educational backgrounds and ethnic differences need to be considered to avert unrealistic expectations on caregiver's ability to be involved in the rehabilitation process. Furthermore, care related requirements post ABI might be compounded by existing strain experienced by caregivers living in conditions where food insecurity and day to day survival is a reality [238].

It is clear that, if intervention is to be regular and effective, the contextual factors related to each child need to be understood and factored into any planning service delivery and realistic intervention plans need to be formulated.

5.3 Aetiological factors (health conditions)

A further possible explanation for the over-representation of children from financially under-resourced homes in the study, is that constrained socio-economic circumstances are viewed as one of the determinants for poor health outcomes [51, 239, 240]. With the likely lack of private transport, children are more likely to attend school and other activities on foot. It is not uncommon for young children to play outside or walk to school unsupervised in low to middle income communities [241], thereby placing them as pedestrians at most risk [242-244] .

As expected, the most common cause of traumatic brain injury for the boys of school going age was a traffic related incident, as reported in another study in the Netherlands [245]. This finding is in line with, other research study findings involving children with ABI [50, 246-248]. In one of the Cape Town studies at Red Cross Children's Hospital, children admitted to trauma units were reported to be mostly boys aged five to 12 and pedestrian traffic related injury was the second most prevalent cause for admission to Red Cross Children's Hospital. In our study, it appears that the younger child was more vulnerable as an unrestrained passenger [244], whilst the older participants sustained their injuries as pedestrians. Furthermore, young children who are less than four years are more likely to sustain an injury close to home [139] caused by falls. Falling is reported as the most prevalent cause of injury in the younger child in South Africa [15].

It is clear that accidents are a major preventable cause of paediatric mortality and morbidity [14-16, 246-251]. There is thus an urgent need for legislation addressing accident prevention, including school based road safety programmes [23]. Childsafe [15] and Arrive Alive in Cape Town are two of the existing organisations providing this service to the South African population. The incidence of road traffic accidents is predicted to rise over the next decade due to the increase in migration to cities coupled with insufficient road safety awareness [23, 148]. In this light, the Facility could possibly take on an advocacy role in accident prevention. Informal discussions with the child and caregiver could be incorporated in therapy sessions.

Ischaemic events were prevalent as a cause of non-traumatic brain injury in the study population, similar to previous study [12, 32]. The children all had significant improvement in their GMFM scores and PEDI Scores, contrary to other study findings showing ischaemia as a determinant for poor recovery [252]. However their Baseline GMFM scores that were above the 70th percentile, should be taken into account.

The predominance of males in the sample is also of concern. The underlying reason for this is unclear from this study. It may be that boys engage in more risky behaviour, but it could also be that boys receive less parental supervision than girls. Whatever the reason, any preventative programme will need to understand the causes better in order to better target prevention.

5.4 Physical gross motor recovery, participation, and functional performance

5.4.1 Patterns of motor recovery and prediction of Week 9 outcome (Activity)

As reported in several papers, one of the major concerns raised by the caregivers in this study was related to the prognosis of their child with regard to attaining or regaining function [253]. The possibility of predicting outcome also allows the therapist to plan effective long-term intervention [254] and to counsel the caregivers appropriately [6]. Based on the graphical representation of the GMFM88, and the PEDI Mobility scores to a lesser extent, it appeared that there was a group of children with ABI who were likely to make a rapid recovery to full motor functioning and showed little improvement over the course of the 13 weeks as they attained full functioning early in the course of the study. These

children were not as easy to identify at the initiation of the study through the GMFCS as they were drawn from levels I, II and III. Although they may suffer from behavioral and cognitive deficits, they were not in need of ongoing physiotherapy to improve motor function. In contrast, the Group B children (GMCS II and III) started from a lower functional base and were thus able to make considerable progress over the course of the study. This group might benefit the most from intensive physiotherapy treatment aimed at reestablishing full motor control. The third group, C, who were severely affected at the start of the study, did not recover as much functional ability within the three months of the study. They were classified as GMFCS level IV and V (severe injury), and although they also made gains in their gross motor ability this was slower than Group B and the GMFM88% score remained below the 40th percentile throughout the study.

Whereas the GMFCS and the GMFM have been used extensively for prognostic purposes in children with CP [253, 255], there is far less literature on the recovery trajectory of children with ABI. The Glasgow Coma scale evoked response potential testing and cognitive measures such as time to follow commands, but only a single, albeit important paper could be found on the reporting on the trajectories of recovery of motor functioning [5] after ABI. Kelly et al. (2014), similarly used the GMFM88 (which they then transformed into the GMFM66) among 74 children, of which four or more repeated measurements were obtained from 31 children. Our current sample was too small to do the same analysis, but their results demonstrated a similar level of heterogeneity in outcomes and recovery trajectories [5]. Of interest was the graphical plot of recovery trajectories children, the three recovery patterns could also be discerned (Table 1, p. 244), with ten children starting from a very low functional base and showing the flat trajectory patterns of recovery, similar to the Groups C identified in our sample. There were also two children who fitted the Group A pattern, of starting with a high score and achieving the ceiling score. The majority of the participants in this study fit the Group B criteria of showing consistent improvement over time. As discussed above, the motor recovery patterns of the children in Group C (GMFCS level four and five) were found to be poorer compared to the children with mild and moderate injury. Significant motor fallout (GMFM88 score below 40%) was present in this group at study cessation.

These findings are similar to those of Beckung et al. (2007) and Kelly et al. (2015) who, based on a longitudinal study with a sample of 317 children with CP, reported that the sequences of gross motor ability reacquisition after ABI was comparable to that of children with CP [6] [140, 256]. Beckung et al. (2007) reported that 75% of children on Level I and II at Baseline achieved 90% of functioning by the age of seven years. The majority of Level III children attained 80%, whereas most of the children on levels IV and V never attained more than 20-30% on the GMFM.

Therapists would be able to discuss the prognosis of these children using evidence based in this study. The GMFM88% appeared to be more useful for prediction of the Week 9 score and the simple algorithm (22+.94*Baseline score) could assist the therapist in planning intervention and giving appropriate advice to the caregivers. This should be done with caution as the sample was small, and the CIs are large.

Although the sample size limited external validity, the gross motor function recovery trajectory of the study participants corresponded to motor recovery patterns described in other studies [257-259]. In addition, although to be used with caution, the therapist would be able to estimate the possible outcome based on the Baseline GMFM88% score, using the algorithm presented in Table 4-11. It is not surprising that the Baseline GMFM88% is both highly correlated and predictive of the Week 9 score.

The implication of the results of the current study is that it may be possible to predict outcomes based on both the GMFCS level and the GMFM88% at admission, which took place a median of 2.8 month (range 0.8-7.1) after injury. It is important to recognise those children who will not recover full function after the insult and to be able to have a rough estimate of the GMFM88 score 9 weeks later. The management of these children should possibly be different to those in Group B who are likely to benefit from physiotherapy aimed at improving impairment and functional limitations. These children and their caregivers are likely to need long term support and intervention might need to be targeted at provision of appropriate appliances, admission to schools for learners with special needs and psychological support and counselling for the family. In other words, contextual and environmental factors might need to be targeted more in their management. This was evident in that the CSI of the caregivers of children in Group C progressively increased over time as the lack of improvement became more apparent.

5.4.2 Relationship between Intervention and change in GMFM scores

The form of intervention, either intensive or intermittent therapy during the first three weeks, did not result in a significantly different improvement between the two groups in motor function or performance. Despite the widely different contexts, this finding reflects that of Christiansen et al. (2008), who explored the application of intermittent versus continuous chain physiotherapy over a period of 30 weeks in a group of 25 children with cerebral palsy, aged one to eight years [44]. Intermittent physiotherapy consisted of therapy given four times a week for four weeks followed by a six-week break. Continuous chain physiotherapy consisted of therapy given once a week. Their study concluded that there was a significant improvement in GMFM scores irrespective of the intervention received. The timing of physiotherapy provision does therefore not appear to be of as much importance as the receiving of therapy. Dumas et al. (2008) reported that treatment intensity was not significantly associated with improved motor outcomes in children with traumatic brain injury [257, 259]. In their study, the relationship between physiotherapy treatment intensity and motor was examined. Findings by Trahan et al. (2002), indicated an improvement in GMFM scores in five children with cerebral palsy, receiving intermittent physiotherapy supported Christiansen's results [183].

Yet, Forsyth et al. (2017) postulate that no conclusive evidence is available to support the impact of rehabilitation on recovery post an acquired brain injury [46, 260]. To address this, they developed a measurement tool, the Paediatric Rehabilitation Ingredients Measure (PRIM), for use in studies to quantify rehabilitation dose and content related to outcomes achieved. Even though the PRIM tool is still a work in progress, the tool generated positives such as communication and discussion between all the heath team members. Kolobe et al. (2014) concurred with the debate on the inconclusiveness of treatment dosage and further recommend that research evidence of a treatment strategy precludes dosage of a particular strategy treatment [176].

Of interest was that, apart from between Week 9 and Week 13, improvement in motor function for the entire group showed a medium effect size from each time point to the next,

which indicates that there was a continuous improvement in GMFM88 score over the course of the nine weeks of the study. The greatest effect size was seen between Baseline and Week 7, and it was during this stage that physiotherapy treatment was given. For the last four weeks of the study, the children were discharged home and received maintenance therapy provided by trained rehabilitation workers employed by the Facility. During this time there was no effect evident with regard to improvement in scores.

It therefore appears that there is no clear evidence to support any model of physiotherapy delivery. However, the medium change that was seen after admission to the Facility, the initiation of therapy, and the continuous improvement until professional support was replaced by rehabilitation workers, might indicate that regardless of time since insult, children with ABI will benefit from physiotherapy intervention.

This finding is supported by Kelly et al. (2015) who, studied patterns of recovery in children admitted to a large residential paediatric rehabilitation facility for children after severe ABI. They concluded that "where it was seen, the 'take-off' in gross motor recovery trajectory coincided approximately with admission. This could reflect a rehabilitation effect, or alternatively that admission was only arranged when a child was deemed 'rehabilitation ready' by showing some early signs of recovery " [5]. Whereas the sample is far too small to generalize, there is some indication that admission to the Facility and regular physiotherapy might be associated with gains in motor score.

Improvement in motor function continued for at least seven weeks post-initiation. This is important for the Facility, as it indicates that all children, are likely to show some benefit in terms of motor control. The role of the rehabilitation workers needs to be examined as the lack of improvement could very well be due to the majority of children having almost having reached their GMFM88 ceiling (over ten had scored more than 90% by Week 9) and it may not be necessary to continue therapy.

On the other hand, the children in Group C were still in need of support and those who were still making progress might benefit more from continued specialised physiotherapy. It appears as if "one size" in therapy is unlikely to meet the different needs of each child. It might be useful for the Facility to routinely use the GMFM88 to identify which children are still improving, which have plateaued, and which have reached their motor ceiling so that

the nature of support, either specialised physiotherapy, occasional check-ups or community-based maintenance is the most appropriate to their needs.

5.4.3 Association between different variables and the change evident in GMFM88%.

A further objective of the study included identifying which factors were predictive of early change in GMFM88% scores from Baseline to Week 3. Unfortunately, the sample was too small to support multi-variate analysis and each factor was analysed separately which might have resulted in confounding. For example, a low GMFM88 might have resulted in longer hospitalisation and a longer time to admission to the Facility and older children might have been more likely to suffer from TBI as opposed to infection and this could have had an influence on their recovery. The results therefore need to be approached with caution.

As reported elsewhere [6], there were no significant difference in recovery rate in the first three weeks between males and females, although a difference might have been masked by the association with gender and cause of injury (all the girls had infective rather than traumatic causes). The age of the child at injury and the time since injury to admission were both negatively correlated with the amount of change evident in the first three weeks of treatment. Furthermore, correlations which might well have been significant if the sample had been larger. This finding is in contrast to other study results showing that the younger child is more vulnerable to severe injury and thus prognosis is poorer [6,97] The argument put forward by Kelly et al. (2015) is that older children are relearning skills whereas younger children need to establish circuitry for the first time. This may be true of their study, as the range of ages was greater than the current study and included infants from the age of three years, whereas the youngest child in the current study was 2.1 years. Four of the five younger children, made greater gains in their motor outcome compared to the older study participants. However, the younger children all started their intervention within three months of their injury onset; whilst the older children started with their intervention after four months of their injury onset, a further example of confounding for which multivariate analysis would have compensated.

The negative correlation found between timing of intervention and injury onset suggests that early intervention may lead to better outcomes, but this is an unproven assumption and there may be other explanations. For example, injury severity has been reported to be related to recovery [164]. Those with more severe injury may have remained in hospital

longer and the time to referral to the Facility could have been delayed. This hypothesis was not supported however and there was no difference in the ranking of time since insult between the different groups. A weakness of the study was that prior rehabilitation intervention was not documented and it is likely that the majority of children referred from the tertiary hospitals would have received physiotherapy in the acute stage of their injury. However, it appears that, similar to other studies [28], a prolonged time since injury to intervention initiation might lead to smaller improvements over time. This could be due to more improvement taking place in the early months after the injury.

5.4.4 PEDI scores (Activity and Participation)

The GMFM and the PEDI have been shown to be complimentary of each other [39, 127]. Use of both scales is recommended, because motor capability is assessed in two different environmental contexts. The GMFM measures the best ability of the child to perform a gross motor activity based on observation by a professional in a structured environment. The PEDI assesses motor capability in relation to usual performance in daily activities within the child's normal living environment based on caregiver report [127]. The use of the functional skills dimensions of the PEDI assessing mobility and self-care were similar to the approach used by Kothari et al. (2003) to measure functional recovery in children with an acquired brain injury [261] .

Although the two instruments rely on different methods of data collection, similar general patterns of change were observed in the PEDI scaled scores as for the GMFM88 scores. Six children achieved 95-100% at Week 7 in all three scales. The same three groups could be discerned but the patterns of recovery were less clear, e.g. the children in Group C appeared to achieve peak mobility performance at Week 7 and then regress. The self-care scale showed more erratic patterns of improvement and more children appeared to plateau, although some did show improvement several weeks later. Compared to the GMFM88, the PEDI scores did not show a medium effect size after Week 7 in (mobility) or Week 3 (self-care), which implies that the children made little progress from these time points on. This might imply that the self-care activities particularly require attention later in therapy and particularly in the period after discharge from the Facility.

The inclusion of both measurements ensures detection of changes in motor capability that might not be detected by the other. Furthermore, both tests take on average 30 to 40

minutes to complete, and assessor time constraints might have influenced results, because the assessor was available mornings only on specific days of the week. Within the study site, where high patient staff ratios exist, the use of both measurements might not be feasible. Moreover, the PEDI was developed due to a need to evaluate the impact of physiotherapy on changes in functional performance within an everyday setting [261]. In that regard, the PEDI might be more applicable for use within an intermediate care setting where the objective is to facilitate participation within daily living.

5.4.5 HRQoL (Participation)

The information gained through the domains of the EQ-5D-Y did not add much new information regarding the mobility and functioning of the child. In general children, were reported to have less severe problems with a corresponding increase in some problems over the course of the study. However, what was concerning was the large number of children reported as being sad and anxious at Baseline and the number of children reporting being worried, sad or unhappy increased from Week 6. This should alert therapists to the need to address the emotional impact of the injury, both on admission to the Facility when the child may be homesick and anxious within a strange environment and in the longer term when improvement may not be as rapid and the child may be becoming aware of their activity limitations.

The Baseline VAS did not correspond with any of the other measures but by Week 9 it was correlated with all of the other measures, although somewhat less than most. It might be that the care-givers were now more certain as to the child's functional abilities and potential and scored the children appropriately. Interestingly, there was a similar increase in the CSI score for the care-givers of the children in Group C and the impact of caring for a child with severe functional limitations is likely to have increased the CSI scores, similar to a study-on - strain experienced by the spouses of stroke patients [262] The sharp increase in caregiver strain in one of the Group B was probably related to the cognitive function and behavioural difficulties that emerged [263], because almost full motor recovery was observed. At study cessation, strain in CSI domains such as change in former self, work adjustments, upsetting behaviour, time demands, personal plans, family adjustments and confining were indicated by this caregiver. There is thus a need for ongoing psychological support and it may be that

in the later stages of rehabilitation the need increases, particularly if the child still has functional or behavioural deficits.

Likewise, the caregiver of one of the children who withdrew from the study, reported a similar pattern of strain. In both these cases, caregiver burden appear to not result from motor functional problems, but was due to a reduction in neurobehavioral function as reported elsewhere [264]. A reduction in neurobehavioral function is consistent with several study findings on the neurobehavioral consequences post TBI [19, 263, 265]. A common concern reported by caregivers were the change from former self, which was also reported in the latter two cases [266]. This was the main concern expressed by these two caregivers for which they sought assistance from the clinical staff. Thus, existing physical difficulties were not priority for them. Notwithstanding the behavioural problems experienced in these two cases, the clinical staff reported that caregiver-child bond were close in these two cases. Therefore, providing caregiver support early on in context of the age and stage of the child's development could reduce caregiver burden [188, 193, 195, 267].

The caregiver's strain cannot be evaluated in isolation without taking into account the impact of confounding variables such as environmental factors (facilitators and barriers), the personality of the caregiver, and premorbid caregiver child relationship [63].

Prior to the study, the researcher assumed that raising road safety awareness amongst caregivers would assist in the prevention of child traffic related accidents. This assumption of the researcher might not be realistic in context of the socio economic and demographic backgrounds the study participants came from. It is generally a norm or accepted for children to play on the streets, walk to school or use public transport such as taxi's or trains to get to their destinations within these communities [16]. Within this context caregivers might already be preoccupied with survival on a day to day bases, causing safety issues to possibly move lower on their list of priorities [268]. Expecting caregivers to take on more than they can cope with might add to caregiver burden. The Facility should thus rather focus on the relief of caregiver burden than "fixing" parental attitude which might applicable in more affluent communities. Mention was also made of the caregiver attitude or lack of involvement within their child's rehabilitation process. The lesser demands in terms of physical care were perceived by caregivers as an improvement on their HRQOL.

It may thus be concluded that as the children improved in their gross motor abilities, their capability to perform in activities of daily living improved. Although the children made gains in their gross motor function over time, problems in cognition, behaviour and psychological functioning emerged over time during the study period. These factors might have affected the health-related quality of life of the participants and caregivers. However, testing of cognitive and behavioural problems fall outside the scope of practice of the researcher and was thus not tested. Notwithstanding, the Caregiver Strain Index does include questions exploring the impact of emotional and behavioural changes on caregiver burden. Behavioural changes affect child- parent interaction leading to increased burden in care [269]. Although not tested, behavioural and emotional changes are noted, because it could have impacted on the motor functional and performance outcomes achieved as well as the reported burden of care by caregivers [270]. The importance of the support and attitudes of care-givers, which are classified as being environmental facilitators in the management of children with ABI, cannot be overestimated. The support to care-givers should be a major goal of rehabilitation intervention, particularly for the children with residual functional limitations, the child can thus not be treated effectively without considering all components of the ICF, functioning and environmental.

5.5 Strengths and Limitations of study

The major weakness of the study was that the sample size was small due to time constraints. This not only limited the statistical analysis that was possible but also the external validity of the study. A cautionary approach is thus adopted by the researcher when interpreting the study results. Sampling was also confined to one facility and thus is not representative of other facilities providing rehabilitation to children with an acquired brain injury. The study results are therefore not generalizable to the wider community of children with ABI. The results however, do highlight several important aspects of the trajectory of recovery and may warrant a larger study.

The study results combined both traumatic and non-traumatic brain injury in analysis and it might have been preferable to do sub-group analyses if the sample size had been large enough to support it. Although there was no significant difference found between the amounts of change in score over the first three weeks, sub-group analysis over time might have revealed differences.

There were certain deficits in the data that were collected. These include the extent and nature of rehabilitation prior to admission to the Facility and the study. In addition, caregiver involvement was not quantified and deductions regarding the impact of the physiotherapy programmes made should thus be viewed with caution.

All the outcome measures were in English. To accommodate for language barriers the assessor instructed the GMFM in Afrikaans when assessing a child whose primary language was Afrikaans. When assessing Xhosa speaking children, the assistance of one of the Facilities RCWs were employed to act as interpreter. The RCW was not trained on the use of the GMFM, but gave instruction as directed by the assessor. Misinterpretation of instruction might then have influenced results of the GMFM, even though the RCW had experience in working with children and has acted in the capacity of interpreter before. A further concern is, that although used satisfactorily in the Facility prior to the study, the PEDI has not been validated for use in the South African context. The version of the PEDI used may not be culturally sensitive to the study population. Functional test items such as managing a seatbelt or car restraint; climbing in and out of a bath and self- care test items such as using a fork, managing tangles and parting hair are not part of the norm for some of the study population. The majority of the study population made use of public transport where the use of car restraints and seatbelts are not common [271]. Some of the participants as pointed out before in the discussion on demographics (section 5.2) lived in informal housing and do not have access to a bath or shower. Children are then typically washed using a basin or bucket. In addition, culturally eating with a spoon is more common than eating with a fork. The use of a modified PEDI version as used by Broughton, et.al (2014) to assess the impact of a five day intensive Bobath therapy programme on the gross motor function and participation of children with Cerebral Palsy in rural South Africa, may have been preferable, although this version was also not validated [45] .

Both the PEDI and the GMFM have been shown to have ceiling effects. Existing motor function problems were not identified in six of the higher functioning children due to ceiling effects in both. The GMFM scores of the children might have been impacted by items of difficulty or those that children have already surpassed developmentally. The children might then have viewed these items as redundant and were poorly motivated to perform these test items. This challenge was experienced during the study, when reduced cooperation and

motivation by a child participant was reflected as a reduction in GMFM scores of one child at the Week 7 measurement point. This child was reluctant to complete the test measurements and cooperation during the assessment session was thus impacted. A newer version of the PEDI called the PEDI-CAT was developed to reduce ceiling effects of the original PEDI [272], this measurement was not employed, because it was not available to the researcher.

The age range of the participants recruited was wide and the study results might not give a realistic reflection of age specific challenges experienced by young preschool or a crèche aged child.

ABI has a great impact on both social and behavioural functioning of children [273] and limitations were not examined in this study as it was deemed beyond the scope of the study and the scope of practice of the researcher. It is acknowledged that this is a major limitation that should be addressed if the impact of ABI in children is to be comprehensively documented.

Despite the above limitations of the study, the STROBE checklist was used to assess the quality of the study and the majority of the criteria were met (Table 5-1).

Table 5.1: Critique of the study using STROBE criteria

Ta	Item No	Recommendation	Comment on current study
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	A longitudinal, prospective cohort design with repeated measures was employed to evaluate the gross motor outcomes of 17 children with an acquired brain injury aged two to 14 years old.
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	The abstract was structured and summarised the aims, methods, results and discussion
Introduction			
Background /rationale	2	Explain the scientific background and rationale for the investigation being reported	The Introduction includes the background to the study and the scientific rationale for examining the different factors relating to recovery after ABI.
Objectives	3	State specific objectives, including any pre-specified hypotheses	Objectives are outlined and explained in section 1.4 pgs. 18 to 19. No hypothesis was provided, because of the descriptive study design.
Methods			
Study design	4	Present key elements of study design early in the paper	A descriptive observational study was employed, to assess the association between the different variables: Change in GMFM score to age injury, injury severity, timing of intervention and the Baseline GMFM score. Refer to abstract, section 1.5 pg. 21 and the methodology chapter3 section 3.1 and 3.2
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	A detailed description of the research site, recruitment, intervention, follow up and study period is given. Refer to section 3.4 to 3.6 pgs. 51 to 54
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up	Inclusion and exclusion criteria used, as well as the recruitment process are explained. Refer to sections 3.2 pgs. 45 to 46 and section 3.4 pgs. 51 to 54

		(*b*) For matched studies, give matching criteria and number of exposed and unexposed	Study sample was too small to support a matched study
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	Main outcome tested was gross motor function Exposures were the socio- economic conditions, family environment and treatment received. The diagnostic criteria were given but were based on patient medical records which may have been incompletely filled in.
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	The GMFM 88 was the primary outcome measure employed to assess change in gross motor function. Both the GMFM and the PEDI assesses gross motor function and have been validated for use in children with an acquired brain injury. Though the GMFM only measures capability to perform a motor task whereas the PEDI evaluates capability and performance. Within a time, constraint environment and the cognitive fall out experienced by some of the participants the selection of one or the other might have been more time saving and appropriate.
Bias	9	Describe any efforts to address potential sources of bias	Study is confined to one study site with a small sample size which could possibly introduce bias on the interpretation of the study results. A blinded assessor not employed at the research site was used to mitigate bias.
Study size	10	Explain how the study size was arrived at	Sample size calculation see table 3-1 pg.47 Reasons for method used is also given in section 3.3.2 pg. 46
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	Quantitative variables were not normally distributed and non-parametric analysis was used. Bivariate analysis was used to establish the determinants of change.
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	The statistical methods are described in Section 3.5 Non-parametric statistics were used due to the non-normal distribution of the data, the ordinal nature of the data and the small sample size.
		(*b*) Describe any methods used to examine subgroups and interactions	Not applicable
		(*c*) Explain how missing data were addressed	Data was still included if data was available for a participant after the Week 3-time measurement

			point
		(*d*) If applicable, explain how loss to follow-up was addressed	Data of participants that was lost to follow up after the Week 3- time measurement point was not included
		(*e*) Describe any sensitivity analyses	N/A
Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—e.g. numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	See figure 4-1 pg58
		(b) Give reasons for non-participation at each stage	The reasons for attrition are presented and discussed
		(c) Consider use of a flow diagram	Flow diagram used as described above
Descriptive data	14*	(a) Give characteristics of study participants (e.g. demographic, clinical, social) and information on exposures and potential confounders	This information is presented in section 4.2 of the results
		(b) Indicate number of participants with missing data for each variable of interest	See table 4-1. pg. 58
		(c) Summarise follow-up time (e.g., average and total amount)	
Outcome data	15*	Report numbers of outcome events or summary measures over time	Participants were in the study for a total of thirteen weeks. See Table 4-7, Table 4-14, Table 4-16, table 4-18 and the median CSI score reduced from seven to four from baseline to week 13 (Table 4-19). In general, the strain level reduced from Baseline in children in the A and B Group and remained high or increased in Group C Children (Table 4-19).

Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (e.g., 95% confidence interval). Make clear which confounders were adjusted for and why they were included	N/A
		(*b*) Report category boundaries when continuous variables were categorized	This was done in the histograms
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	Risk analysis was not done
Other analyses	17	Report other analyses done—e.g. analyses of subgroups and interactions, and sensitivity analyses	N/A
Discussion			
Key results	18	Summarise key results with reference to study objectives	This was done in 4.12, Summary of findings and 5.1. Introduction to the Discussion.
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	This was done in Section 5.5, Strengths and Limitations of study
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	This was done in Chapter 5, Discussion
Generalisability	21	Discuss the generalisability (external validity) of the study results	Discussed in Chapter 5 Discussion under Introduction and throughout the discussion.
Other information			
Funding	22	Give the source of funding and the role of the funders	Not applicable

		for the present study and, if applicable, for the original study on which the present article is based	

Chapter 6. Conclusion and recommendations

Despite the limitations of the study, useful information was gathered which can inform the provision of physiotherapy and rehabilitation services at the Facility. Based on these results, recommendations are made for clinical practice at the Facility, further study, and policy and advocacy responses.

6.1 Clinical recommendations

As the form of service delivery did not appear to impact on outcome, both the intensive and intermittent physiotherapy treatment approaches could be of benefit to the children accessing the Facility. The intensive regime could be useful to those caregivers who indicate a need to have their child home as soon as possible to resume a sense of normalcy in their lives post injury. On the other hand, the intermittent treatment approach might be more suited for some caregivers.

Rehabilitation care plans should be established based on the projected recovery trajectory and the Facility should develop individualised programmes for children in each of the three Groups. Although, most children regained physical functioning, approximately four of the children admitted for rehabilitation with ABI might have significant residual motor damage and will need on-going rehabilitation support. A further four demonstrated rapid and almost complete recovery and might well have benefited from the rehabilitation and physiotherapy offered. Half of the children had very little motor fallout and their motor rehabilitation could concentrate on re-establishing more advanced motor control and possibly physical fitness through games, sport, and physical activity in therapy.

It could be that children in Group A and B would benefit most from a shorter period of intensive therapy, whereas those in Group C might need long-term, intermittent therapy. This approach would need to be tested within the clinic as it was not proven in the current study. It would also require the mandatory assessment of each child on admission using the GMFCS and the GMFM66 to determine the recovery trajectory early on. It is recommended that the GMFM66 be used as a routine outcome measure as suggested by Kelly et al. (2015)

[6] as it is shorter and less tiring for children with ABI, particularly in the early stages. The PEDI mobility which was lengthy, time-consuming, and more difficult to score is not recommended for routine use. The PEDI self-care domain did provide unique information, but it would need to be validated before being introduced as a routine measure.

In terms of treatment content, techniques might be more focused on impairments of body function, structure and basic activity for the lower functioning child with severe activity limitations. Treatment strategies that are more geared to the facilitation of active assisted movements, maintaining range of movement and reducing secondary complications could be planned. Compensatory mechanisms such as assistive and mobility devices may be put in place to enable participation. In contrast, treatment goals for the higher functioning child may be more focused on skills acquisition to enable participation. Decisions on which resources are required to enable participation should be made based on the projected recovery trajectories, as should the long term strategies for increasing participation in the community post-discharge. Identification of the determinants of motor recovery may guide intervention planning to address areas that require specific attention for successful reintegration post discharge [30, 140].

The high levels of strain reported at admission and the continuing high levels in some care-givers, warrants early provision of support and counselling. Currently the Facility does monitor and provide support to caregivers post discharge via a rehabilitation care worker. However, more skilled psychological support might be necessary earlier, particularly for those care-givers who have children in Group C or who have behavioural problems. The CSI is easy to administer and should also be routinely administered to ensure that the caregivers do get the level of psychological support that they need. The Facility should continue to provide the post-discharge service to identify difficulties or emerging problems. Appropriate referral or top up therapy can then be initiated when required.

Similarly, the large proportion of children who were reported to be “Worried, sad or unhappy” (two thirds of the sample at Week 13) needs to be addressed and psychological support should be extended to the children as well. In order to monitor the HRQoL of the children, it is recommended that the EQ-5D-Y be used at regular intervals, either the proxy version 1 or the self-report version if the child is over 8 years of age and able to respond.

Practical steps that could be taken to reduce the CSI include

- Schedule appointment to minimise disruptions to work times and family routines.
- Assist families with grant applications as needed for financial assistance
- Be open to be guided by caregivers in terms of how much they can cope with at a given time, thus adopt a family and person-centred approach.
- Encourage caregivers in the drawing up of care and discharge plans early within the rehabilitation process when they are available and when the recovery trajectory of their child becomes apparent.
- Accept caregiver decision to not be involved in the rehabilitation process. Find alternative means of ensuring the child get the care they need once discharged. Identify someone else who might be able to assist in the care of the child post discharge.

In addition, a remark made by some caregivers was that they wanted their children to stay at the Facility no matter the length of stay, as long as their child obtained close to or premorbid function and independence. Having their child at the Facility until optimal motor recovery has been achieved and might thus reassure caregivers. It might also be that having their child's day to day needs being catered for at the Facility allows the care-givers some respite to deal with their own financial problems and caring for others in the family. Caregiver respite may well be a valid goal of management of children with ABI.

6.2 Recommendations for further study

The above recommendations are based on a small sample of children and the impact of each should be tested as far as possible. If the GMFCS, the GMFM66, the EQ-5D-Y and the CSI are routinely administered at admission and at regular intervals, it might be possible to validate the findings of this study and to develop better prognostic recovery trajectories for the different subgroups of children with ABI. In addition, the results are based on a relatively short period of time and the same measures should be applied at regular, although possibly longer, periods after discharge to better understand the long-term implication of ABI in the Cape Town context.

It might be possible to introduce such a routinely administered minimum data set across all similar facilities in South Africa that cater to the rehabilitation needs of children with ABI. This would result in a much larger, on-going data set which could be managed as part of an

on-going study and would yield extremely useful insights into the recovery patterns and rehabilitation needs of children with ABI.

It was not possible to explore the impact of different forms of service delivery adequately in this study and, as mentioned in the literature review, there is little evidence regarding the impact of different forms of physiotherapy intervention delivery on functional motor outcomes and performance in children with ABI. Randomised control trials (RCT) are the study design of choice for intervention studies, but there are obvious ethical concerns with the use of placebo groups in vulnerable children. Once recovery trajectories for the different sub-groups are established, these can be used to test for the differential impact of different intervention strategies, as suggested by Kelly et al. (2015) [6].

The PEDI self-care domain should be validated before further use but, as it provides unique information, this might be a useful exercise.

6.3 Recommendations for advocacy and policy development.

The research evidence, coupled with other published epidemiological evidence related to ABI in the Western Cape, should be used to establish prevention and safety awareness programmes at the Facility as part of the service care provided. The Facility rehabilitation service provision embeds the Children's Act, thus, the child's right to safety and security underpins service provision at the Facility. Furthermore, children admitted to the Facility come mostly from resource poor communities according to its database described in chapter one. The aforementioned socioeconomic conditions have been linked to a high incidence of ABI in children [231]. Thereby, the Facility could take on an advocacy role for the safety of these children through collaborative work with agencies such as Childsafe, which is already based within the catchment communities of the Facility. On-site safety awareness programmes could be established, for example in the form of posters and formal and informal talks. Safety awareness at home could be created via the Facility's rehabilitation care workers during home visits, by identifying risk factors within the home or within the surrounding areas of the children's home environment [228]. These should also target the non-accidental injuries in the older boys.

Little improvement was seen between Week 9 and 13, when the children were no longer receiving professional support. Thus, the need for on-going support within the community

for children who are likely to be left with severe residual damage is clear and the role of community-based workers is likely to be important. These workers should all receive a basic level of training, followed up by regular continuing education sessions. The results of this study, for example, should be shared with these workers. The possibility of placing physiotherapy students with the workers as part of community clinical training blocks could also be explored as it has been found that home-based carers skills and knowledge improve when physiotherapy students are placed with them [274].

6.4 Concluding remarks

Most of the children with acquired brain injury who participated in this study were drawn from circumstances of extreme deprivation and poverty. Many of the care-givers were women who received little support from the father of the child and had to contend with financial stresses and the responsibilities of caring for other children. It is thus essential that the Facility provide optimal supportive care, not only to the children but to their families as well. In order to do so, it is necessary to understand the holistic needs of the children, their expected recovery trajectories and the constraints to caregiver participation in treatment.

It is hoped that the results of this thesis will motivate all the physiotherapists at the Facility to adopt a holistic patient and family centred approach to meet the needs of the child and their caregivers. This might entail the development of targeted packages of care, based on the predicted pattern of gross motor recovery. In addition, the need for on-going care, among the most severely affected children, should be recognised. Long- term strategies to reduce the anxiety levels of the child and the strain on the care-giver should be put into place.

These children deserve a chance to reach their full potential!

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Appendices

Appendix 1

Informed consent

Dear Sir/ Madam

My name is Faiza Achmat and I am doing my masters study in physiotherapy at the University of Cape Town. My study involves looking at how we can improve therapy service delivery to children who have sustained damage to their brain. My supervisor is Professor. J. Jelsma. To protect the rights and safety of persons participating in this study approval from the Research and Ethical Committee, Faculty of Health Sciences at the University of Cape Town has been given.

Please read the content of this letter carefully before making a decision to participate in this study or not.

We are asking you to allow your child to take part in this study as he or she had some damage to his or her brain during the last year. We want to see if treatment given every day over two weeks will lead to an improvement in what they are able to do. The study will be conducted at St Joseph's Children's Home (SJH) which is in Montana, close to communities such as Bonteheuwel, Heideveld, Guguletu, Delft, Valhalla Park and Bishop Lavis. We are looking for children aged two to 13 years old to participate in the study. The child must also be medically stable in other words he or she must not be so sick that they still require a doctor help on a daily basis.

You will be asked to come with your child to St Joseph's Children's Home and he or she will be can attend the study on an in or outpatient basis for a period of two or eight weeks. If your child stays in, then we would like you to stay with him or her if possible and accommodation is available on site should you wish to stay in.

When you and your child are transferred to SJH for therapy then the following tests will be done to test what your child can do:

1. A test taking about 15 to 45 minutes will be done to see how well your child can move about.
2. We will also test to see how much assistance your child need in everyday things such as brushing his or her hair, toileting and eating. You will also be asked for information on your child's ability to perform these tasks.
3. You will then be asked to answer a few questions on a sheet of paper on how your life has been affected by your child's illness or condition. Someone will be available should you require help with filling in the answers.
4. If your child is able to, then we will ask him or her answer questions on how their lives has been affected by their condition or illness if not, then you will be asked to answer on their behalf.

All of the above should take about an hour to complete.

You will then be asked to take a card from an envelope. Half the cards will show that your child will get treatment of daily therapy for two weeks a Week after the tests are done. The other half will show that your child will only start treatment six weeks later. Unfortunately, we cannot change when the child will receive his or her therapy once you have chosen a card, because this will interfere with the study. Should you draw a card that shows that your child will receive therapy six weeks later, a referral will be made to your nearest community health care clinic for your child to receive therapy during this time? However, you will be asked to bring your child to The Facility every two weeks during this six -week delay and the same tests done during the first week will be repeated to see if there is any change in your child's ability to do something. If you cannot attend at the right time, then your child will not be able to take part in the study. If you do not wish to take part in the study, then your child will continue to receive therapy once a Week for six months as part of our normal inpatient therapy programme. Alternatively, we will we will refer you to your nearest rehabilitation centre for follow-up treatment if you request it.

After your child has completed their two weeks of daily therapy, the same tests will be done again. Your child will then be discharged home. A rehabilitation care worker will come to your home weekly for four weeks to provide home based therapy to your child and to give you support where possible. Because we will need to see how your child is doing, we will ask

you to bring the child back for the same tests, after two, four and twelve weeks of being home.

All the tests will be done by trained therapists. Great care will be taken to ensure that no harm will be done during this process. By your choice you can sit in and participate in the assessment process.

Please note your participation in this study is completely voluntary and you are able to withdraw at any time. No explanation for your withdrawal will be needed and it will not affect your ability to come to SJH in the future for therapy. The researcher does however request that you please inform her should you decide to withdraw. We are willing to refer your child for rehabilitation to community health care facility or district hospital in your area should you request this.

No payment will be given and no other associated benefits besides receiving therapy will be derived from participation in the study. Therapy, accommodation and meals for you and your child given at SJH will be free of charge. You will be provided with transport money or transport where possible to come to SJH for the follow up appointments two, four and twelve weeks after having been discharged. You will be given something to eat and drink on the days that you come for the tests.

All information gathered on you and your child will be kept confidential. Your and your child's names and personal details will not be revealed in the study and any articles that might be published in the future. We hope that this is clear, but if there are any further questions or problems that should come up, please feel free to get in touch with myself or my supervisor or Professor Marc Blockman from the UCT Human Research Ethics Committee.

Contact details

Faiza Achmat

0219340352

Email: therapeuticmanager@stjosephshome.org.za

Supervisor Email: Jennifer.jelsma@uct.ac.za

Professor Marc Blockman

Chair: Human Research Ethics Committee, Old Main Building Groote Schuur Hospital, Floor E52, Room 23, Observatory, 7925.

Statement of consent

I ……..have read (or was read to me by ……..) the information letter . I understand the content of the information letter and the role that my child and I am required to full fill in the research study. An opportunity was given to me to ask questions and my questions were answered. I understand that my participation in the research study is completely voluntary, of my own free will and that I can withdraw at any time without affecting me and my child in anyway.

Signed:

…….

……..

Participant Date and place

…….

……..

Researcher Date and place

…….

……..

Witness Date and place

Appendix 2

Informed Assent

Dear Participant

Please read this letter or ask someone to read this letter carefully to you before you decide to participate in this study or not.

My name is Faiza Achmat and I want to know if doing exercises can help you do things such as eating and moving a bit more easily. We don't know if the exercises will help so we need your help to find this out.

When you and your parent agree to participate in the study, your parent will draw a card to see if you will come to St Joseph's for two weeks of therapy exercises. You might stay at The Facility during this time if your parent chooses this and your parent is welcome to stay with you during your time at The Facility.
When you are in The Facility, we will do some tests to see how well you are able to move and look after yourself. We will then give you exercises every day and then test you every few weeks to see if you are making progress.

You do not have to take part in this study and if you say that you do not want to come to St Joseph's you will not be forced to do so. We will then send you to another centre for exercises. You will be able to come back to St Joseph's after the study is done.

You will not get any money for taking part, but we will give you transport money and food to you whilst you are taking part in the study. Please ask questions if things are not clear to you or you do not understand what you will be asked to do.

Contact details

1. Faiza Achmat

Tel: 0219340352

Email: therapeuticmanager@stjosephshome.org.za

2. Supervisor: Professor Jennifer Jelsma

Email: jennifer.jelsma@uct.ac.za

3. Chair Research Ethics Committee: Professor Marc Blockman

UCT Faculty of Health Sciences

Tel: 0027(21) 406-6492

Statement of assent

I ……..have read (or was read to me by …….) the information letter . I understand the content of the information letter and the role that I am required to full fill in the research study. An opportunity was given to me to ask questions and my questions were answered. I understand that my participation in the research study is completely voluntary, of my own free will and that I can withdraw at any time without affecting me in anyway.

Signed:

…….

……..

Participant Date and place

…….

……..

Researcher Date and place

…….

……..

Witness Date and place

Appendix 3

NO FAULT INSURANCE CLAUSE
Human Research Ethics Committee, Faculty of Health Sciences, University of Cape Town

Clause – Insurance in Consent Form

In industry-sponsored clinical research, the consent form **must** include a simply-worded statement that research-related injuries will be compensated according to the provisions of the SA Department of Health's 2006 SA GCP guidelines (based on the Association of the British Pharmaceutical Industry (ABPI) Clinical Trial Compensation Guidelines).

In investigator-initiated research, which relies on UCT's No Fault Insurance policy, the consent form **must** include the following text:

What if Something Goes Wrong?

The University of Cape Town (UCT) has insurance cover for the event that research-related injury or harm results from your participation in the trial. The insurer will pay all reasonable medical expenses in accordance with the South African Good Clinical Practice Guidelines (DoH 2006), based on the Association of the British Pharmaceutical Industry Guidelines (ABPI) in the event of an injury or side effect resulting directly from your participation in the trial. You will not be required to prove fault on the part of the University.

The University **will not be liable** for any loss, injuries and/or harm that you may sustain where the loss is caused by

- The use of unauthorised medicine or substances during the study
- Any injury that results from you not following the protocol requirements or the instructions that the study doctor may give you
- Any injury that arises from inadequate action or lack of action to deal adequately with a side effect or reaction to the study medication✸
- An injury that results from negligence on your part✸

[✸Researchers must bear in mind that it is unacceptable to impose a burden on participants who may not recognize symptoms or have the ready means to take action.]

“By agreeing to participate in this study, you do not give up your right to claim compensation for injury where you can prove negligence, in separate litigation. In particular, your right to pursue such a claim in a South African court in terms of South African law must be ensured. Note, however, that you will usually be requested to accept that payment made by the University under the SA GCP guideline 4.11 is in full settlement of the claim relating to the medical expenses. “

An injury is considered trial-related if, and to the extent that, it is caused by study activities. You must notify the study doctor immediately of any side effects and/or injuries during the trial, whether they are research-related or other related complications.

UCT reserves the right not to provide compensation if, and to the extent that, your injury came about because you chose not to follow the instructions that you were given while you were taking part in the study. Your right in law to claim compensation for injury where you prove negligence is not affected. Copies of these guidelines are available on request.

August 2014

Appendix 4

Landrum Rehabilitation outcome levels

Outcome Level Zero

Medically Unstable

Outcome Level one – physiologic stability

All major medical and physiological problems have been addressed. Medical stability achieved. Can be discharged from an acute setting

Outcome Level Two- Basic rehabilitation outcome

Limited level of independence in self- care, mobility, safety, and communication. Max supervision and assistance required

Outcome Level Three- Intermediate rehabilitation outcome

Moderate level of functional independence in self-care, mobility, safety, communication, and home plus community integration. Min supervision and assistance required.

Outcome Level Four- advanced rehabilitation outcome. Community integration

Max level of independence at an appropriate level within the community or home setting.

This include maximal independence in self- care, mobility, safety and communication and home and community integration. Min supervision and assistance required.

Outcome level Five-Productive activity

Re- establishing the patient in productive activity taking into consideration account his or her capacity. This include vocational or educational areas. Some supervision and assistance may be required

Appendix 5: HREC approval certificate

UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Human Research Ethics Committee

Room E52-24 Old Main Building
Groote Schuur Hospital
Observatory 7925
Telephone [021] 406 6338 • **Facsimile** [021] 406 6411
Email: shuretta.thomas@uct.ac.za
Website: www.health.uct.ac.za/fhs/research/humanethics/forms

25 February 2016

HREC REF: 831/2015

Prof J Jelsma
Physiotherapy
F-Floor, OMB

Dear Prof Jelsma

PROJECT TITLE: THE IMPACT OF A TWO WEEK INTENSIVE BLOCK OF THERAPY ON THE FUNCTIONAL OUTCOMES OF CHILDREN AGED SIX MONTHS TO 13 YEARS POST AND ACQUIRED BRAIN INJURY. (MSc candidate- Ms F Achmat)

Thank you for your response to the Faculty of Health Sciences Human Research Ethics Committee dated 15 February 2016.

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study.

Approval is granted for one year until the 28th February 2017.

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.
(Forms can be found on our website: www.health.uct.ac.za/fhs/research/humanethics/forms)

Please quote the HREC REF in all your correspondence.

We acknowledge that the student, Faiza Achmat will also be involved in this study.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Yours sincerely

pp T.Burgess

PROFESSOR M BLOCKMAN
CHAIRPERSON, FHS HUMAN RESEARCH ETHICS COMMITTEE
Federal Wide Assurance Number: FWA00001637.
Institutional Review Board (IRB) number: IRB00001938
This serves to confirm that the University of Cape Town Human Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Convention on Harmonisation Good Clinical Practice (ICH GCP), South African Good Clinical Practice Guidelines (DoH 2006), based on the Association of the British Pharmaceutical Industry Guidelines (ABPI),and Declaration of Helsinki (2013) guidelines.

HREC REF 831/2015

Appendix 6: Letter to referring hospitals

UNIVERSITY OF CAPE TOWN

Faculty of Health Sciences

Department of Health and Rehabilitation Sciences

Divisions of Communication Sciences and Disorders, Nursing and Midwifery, Occupational Therapy, Physiotherapy; and Disability Studies

F45 Old Main Building, Groote Schuur Hospital

Observatory, Cape Town, W Cape, 7925

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12 April2016

Dear Colleagues

I am currently busy with a Masters study in Physiotherapy at the University of Cape Town under the guidance and supervision of Professor Jennifer Jelsma. Approval from the Research and Ethical Committee, Faculty of Health Sciences at the University of Cape Town has been given to protect the rights and safety of persons participating in this study.

My study aim to evaluate the impact of a two week daily physiotherapy programme, given within six to eight months of the brain injury onset, on the gross motor functional abilities of children post an acquired brain injury aged 6 months to 13 years.

The objectives of the study are to determine if there is a significant difference in the change in gross motor function scores between children attending an intervention program, immediately post baseline assessments, consisting of two weeks of intensive therapy compared to those who receive standard of care followed by the same deferred physiotherapy programme starting six weeks later.
Further objectives are to determine:

- If the functional gross motor goals achieved are maintained for four and twelve weeks after the intervention, with the provision of weekly home- based support by a rehabilitation care worker.

- If parent involvement in the rehabilitation process is related to the maintenance of functional abilities (i.e. activity limitations and participation restrictions) post discharge.

Changes in scores will be determined by the following outcome measures:

- in functional gross motor skills as measured by the Gross Motor Function Measure 66 (GMFM66),
- in their participation as measured by Paediatric Evaluation of Disability Inventory (PEDI),
- In health -related quality of life of parents and the children using the Caregiver Strain Index (CSI) and EQ-5DY respectively.

The study will be conducted at St Joseph's Home (SJH) and I am aiming to recruit a total of 52 children referred to St Joseph's Home for rehabilitation to participate in the study. I will approach the parent/legal guardian one week post admission at SJH to inform and invite them and their child to participate in the study. If a parent/ legal guardian agrees to the study, the child will receive daily therapy for two weeks either immediately or after a period of six weeks. Children in the deferred group will receive therapy as per normal at SJH during the waiting period. Parent education and training will form part of the intervention given. The child will be discharged home post their two weeks of intensified therapy and home- based support from a rehabilitation care worker for four weeks will commence. Any child requiring further therapy after participating in the study will be reabsorbed into the normal SJH rehabilitation programme. Alternatively, they will be referred for follow-up and further intervention at their nearest community health care clinic or where available, their district therapy team.

This letter serves to inform you of the study and to make you aware of the intervention that patients referred for rehabilitation from your facility might receive at SJH. I therefore humbly request that should you identify a patient at your facility that might benefit from this level of intervention that a referral is made for intermediate rehabilitation at St Joseph's Home.

Please feel free to contact the following persons should you have further queries:

1. Faiza Achmat (Researcher)
   Tel: 0219340352
   Email: therapeuticmanager@stjosephshome.org.za

2. Professor Jennifer Jelsma (Research Supervisor)
   Tel: 021406401
   Email: jennifer.jelsma@uct.ac.za

For any questions regarding ethics the following person can be contacted should you not feel satisfied with the answers provided by the researchers:

Professor Marc Blockman
Chair: The Research and Ethical Committee,
Faculty of Health Sciences at the University of Cape Town,
Old Main Building Groote Schuur Hospital,
Floor E52,
Room 23,
Observatory,
7925.
Tel: 0027(21) 4066492

Appendix 7: Instrumentation

Gross Motor Function Classification System

GMFCS Classification Levels are:

- GMFCS Level I – walks without limitations.
- GMFCS Level II – walks with limitations. Limitations include walking long distances and balancing, but not as able as Level I to run or jump; may require use of mobility devices when first learning to walk, usually prior to age 4; and may rely on wheeled mobility equipment when outside of home for traveling long distances.
- GMFCS Level III – walks with adaptive equipment assistance. Requires hand-held mobility assistance to walk indoors, while utilizing wheeled mobility outdoors, in the community and at school; can sit on own or with limited external support; and has some independence in standing transfers.
- GMFCS Level IV – self-mobility with use of powered mobility assistance. Usually supported when sitting; self-mobility is limited; and likely to be transported in manual wheelchair or powered mobility.
- GMFCS Level V – severe head and trunk control limitations. Requires extensive use of assisted technology and physical assistance; and transported in a manual wheelchair, unless self-mobility can be achieved by learning to operate a powered wheelchair.

GROSS MOTOR FUNCTION MEASURE (GMFM)
SCORE SHEET (GMFM-88 and GMFM-66 scoring)

Child's Name: _____ ID#: _____

Assessment Date: _____ year / month / day

GMFCS Level[1]: ☐ I ☐ II ☐ III ☐ IV ☐ V

Date of Birth: _____ year / month / day

Chronological Age: _____ year / month / day

Evaluator's Name: _____

Testing Condition (e.g., room, clothing, time, others present):

_____

The GMFM is a standardized observational instrument designed and validated to measure change in gross motor function over time in children with cerebral palsy. The scoring key is meant to be a general guideline. However, most of the items have specific descriptors for each score. It is imperative that the guidelines contained in the manual be used for scoring each item.

SCORING KEY

0 = does not initiate
1 = initiates
2 = partially completes
3 = completes
9 (or leave blank) = not tested (NT) [used for the GMAE-2 scoring*]

It is important to differentiate a true score of "0" (child does not initiate) from an item which is Not Tested (NT) if you are interested in using the GMFM-66 Ability Estimator (GMAE) Software.

*The GMAE-2 software is available for downloading from www.canchild.ca for those who have purchased the GMFM manual. The GMFM-66 is only valid for use with children who have cerebral palsy.

Contact for Research Group:
CanChild Centre for Childhood Disability Research,
Institute for Applied Health Sciences, McMaster University,
1400 Main St. W., Room 408,
Hamilton, ON Canada L8S 1C7
Email: canchild@mcmaster.ca Website: www.canchild.ca

CanChild
Centre for Childhood Disability Research

[1]GMFCS level is a rating of severity of motor function. Definitions for the GMFCS-E&R (expanded & revised) are found in Palisano et al. (2008). Developmental Medicine & Child Neurology. 50:744-750 and in the GMAE-2 scoring software. http://motorgrowth.canchild.ca/en/GMFCS/resources/GMFCS-ER.pdf

Check (3) the appropriate score: if an item is not tested (NT), circle the item number on the right column

Item		A: LYING & ROLLING	SCORE				NT
	1.	SUP, HEAD IN MIDLINE: TURNS HEAD WITH EXTREMITIES SYMMETRICAL	0☐	1☐	2☐	3☐	1.
*	2.	SUP: BRINGS HANDS TO MIDLINE, FINGERS ONE WITH THE OTHER	0☐	1☐	2☐	3☐	2.
	3.	SUP: LIFTS HEAD 45°	0☐	1☐	2☐	3☐	3.
	4.	SUP: FLEXES R HIP & KNEE THROUGH FULL RANGE	0☐	1☐	2☐	3☐	4.
	5.	SUP: FLEXES L HIP & KNEE THROUGH FULL RANGE	0☐	1☐	2☐	3☐	5.
*	6.	SUP: REACHES OUT WITH R ARM, HAND CROSSES MIDLINE TOWARD TOY	0☐	1☐	2☐	3☐	6.
*	7.	SUP: REACHES OUT WITH L ARM, HAND CROSSES MIDLINE TOWARD TOY	0☐	1☐	2☐	3☐	7.
	8.	SUP: ROLLS TO PR OVER R SIDE	0☐	1☐	2☐	3☐	8.
	9.	SUP: ROLLS TO PR OVER L SIDE	0☐	1☐	2☐	3☐	9.
*	10.	PR: LIFTS HEAD UPRIGHT	0☐	1☐	2☐	3☐	10.
	11.	PR ON FOREARMS: LIFTS HEAD UPRIGHT, ELBOWS EXT., CHEST RAISED	0☐	1☐	2☐	3☐	11.
	12.	PR ON FOREARMS: WEIGHT ON R FOREARM, FULLY EXTENDS OPPOSITE ARM FORWARD	0☐	1☐	2☐	3☐	12.
	13.	PR ON FOREARMS: WEIGHT ON L FOREARM, FULLY EXTENDS OPPOSITE ARM FORWARD	0☐	1☐	2☐	3☐	13.
	14.	PR: ROLLS TO SUP OVER R SIDE	0☐	1☐	2☐	3☐	14.
	15.	PR: ROLLS TO SUP OVER L SIDE	0☐	1☐	2☐	3☐	15.
	16.	PR: PIVOTS TO R 90° USING EXTREMITIES	0☐	1☐	2☐	3☐	16.
	17.	PR: PIVOTS TO L 90° USING EXTREMITIES	0☐	1☐	2☐	3☐	17.
		TOTAL DIMENSION A					

Item		B: SITTING	SCORE				NT
*	18.	SUP, HANDS GRASPED BY EXAMINER: PULLS SELF TO SITTING WITH HEAD CONTROL	0☐	1☐	2☐	3☐	18.
	19.	SUP: ROLLS TO R SIDE, ATTAINS SITTING	0☐	1☐	2☐	3☐	19.
	20.	SUP: ROLLS TO L SIDE, ATTAINS SITTING	0☐	1☐	2☐	3☐	20.
*	21.	SIT ON MAT, SUPPORTED AT THORAX BY THERAPIST: LIFTS HEAD UPRIGHT, MAINTAINS 3 SECONDS	0☐	1☐	2☐	3☐	21.
*	22.	SIT ON MAT, SUPPORTED AT THORAX BY THERAPIST: LIFTS HEAD MIDLINE, MAINTAINS 10 SECONDS	0☐	1☐	2☐	3☐	22.
*	23.	SIT ON MAT, ARM(S) PROPPING: MAINTAINS, 5 SECONDS	0☐	1☐	2☐	3☐	23.
*	24.	SIT ON MAT: MAINTAIN, ARMS FREE, 3 SECONDS	0☐	1☐	2☐	3☐	24.
*	25.	SIT ON MAT WITH SMALL TOY IN FRONT: LEANS FORWARD, TOUCHESTOY, RE-ERECTS WITHOUT ARM PROPPING	0☐	1☐	2☐	3☐	25.
*	26.	SIT ON MAT: TOUCHES TOY PLACED 45° BEHIND CHILD'S R SIDE, RETURNS TO START	0☐	1☐	2☐	3☐	26.
*	27.	SIT ON MAT: TOUCHES TOY PLACED 45° BEHIND CHILD'S L SIDE, RETURNS TO START	0☐	1☐	2☐	3☐	27.
	28.	R SIDE SIT: MAINTAINS, ARMS FREE, 5 SECONDS	0☐	1☐	2☐	3☐	28.
	29.	L SIDE SIT: MAINTAINS, ARMS FREE, 5 SECONDS	0☐	1☐	2☐	3☐	29.
*	30.	SIT ON MAT: LOWERS TO PR WITH CONTROL	0☐	1☐	2☐	3☐	30.
*	31.	SIT ON MAT WITH FEET IN FRONT: ATTAINS 4 POINT OVER R SIDE	0☐	1☐	2☐	3☐	31.
*	32.	SIT ON MAT WITH FEET IN FRONT: ATTAINS 4 POINT OVER L SIDE	0☐	1☐	2☐	3☐	32.
	33.	SIT ON MAT: PIVOTS 90°, WITHOUT ARMS ASSISTING	0☐	1☐	2☐	3☐	33.
*	34.	SIT ON BENCH: MAINTAINS, ARMS AND FEET FREE, 10 SECONDS	0☐	1☐	2☐	3☐	34.
*	35.	STD: ATTAINS SIT ON SMALL BENCH	0☐	1☐	2☐	3☐	35.
*	36.	ON THE FLOOR: ATTAINS SIT ON SMALL BENCH	0☐	1☐	2☐	3☐	36.
*	37.	ON THE FLOOR: ATTAINS SIT ON LARGE BENCH	0☐	1☐	2☐	3☐	37.
		TOTAL DIMENSION B					

Item		E: WALKING, RUNNING & JUMPING	SCORE				NT
*	65.	STD, 2 HANDS ON LARGE BENCH: CRUISES 5 STEPS TO R	0☐	1☐	2☐	3☐	65.
*	66.	STD, 2 HANDS ON LARGE BENCH: CRUISES 5 STEPS TO L	0☐	1☐	2☐	3☐	66.
*	67.	STD, 2 HANDS HELD: WALKS FORWARD 10 STEPS	0☐	1☐	2☐	3☐	67.
*	68.	STD, 1 HAND HELD: WALKS FORWARD 10 STEPS	0☐	1☐	2☐	3☐	68.
*	69.	STD: WALKS FORWARD 10 STEPS	0☐	1☐	2☐	3☐	69.
*	70.	STD: WALKS FORWARD 10 STEPS, STOPS, TURNS 180°, RETURNS	0☐	1☐	2☐	3☐	70.
*	71.	STD: WALKS BACKWARD 10 STEPS	0☐	1☐	2☐	3☐	71.
*	72.	STD: WALKS FORWARD 10 STEPS, CARRYING A LARGE OBJECT WITH 2 HANDS	0☐	1☐	2☐	3☐	72.
*	73.	STD: WALKS FORWARD 10 CONSECUTIVE STEPS BETWEEN PARALLEL LINES 20cm (8")APART	0☐	1☐	2☐	3☐	73.
*	74.	STD: WALKS FORWARD 10 CONSECUTIVE STEPS ON A STRAIGHT LINE 2cm (3/4") WIDE	0☐	1☐	2☐	3☐	74.
*	75.	STD: STEPS OVER STICK AT KNEE LEVEL, R FOOT LEADING	0☐	1☐	2☐	3☐	75.
*	76.	STD: STEPS OVER STICK AT KNEE LEVEL, L FOOT LEADING	0☐	1☐	2☐	3☐	76.
*	77.	STD: RUNS 4.5m (15'), STOPS & RETURNS	0☐	1☐	2☐	3☐	77.
*	78.	STD: KICKS BALL WITH R FOOT	0☐	1☐	2☐	3☐	78.
*	79.	STD: KICKS BALL WITH L FOOT	0☐	1☐	2☐	3☐	79.
*	80.	STD: JUMPS 30cm (12") HIGH, BOTH FEET SIMULTANEOUSLY	0☐	1☐	2☐	3☐	80.
*	81.	STD: JUMPS FORWARD 30 cm (12"), BOTH FEET SIMULTANEOUSLY	0☐	1☐	2☐	3☐	81.
*	82.	STD ON R FOOT: HOPS ON R FOOT 10 TIMES WITHIN A 60cm (24") CIRCLE	0☐	1☐	2☐	3☐	82.
*	83.	STD ON L FOOT: HOPS ON L FOOT 10 TIMES WITHIN A 60cm (24") CIRCLE	0☐	1☐	2☐	3☐	83.
*	84.	STD, HOLDING 1 RAIL: WALKS UP 4 STEPS, HOLDING 1 RAIL, ALTERNATING FEET	0☐	1☐	2☐	3☐	84.
*	85.	STD, HOLDING 1 RAIL: WALKS DOWN 4 STEPS, HOLDING 1 RAIL, ALTERNATING FEET	0☐	1☐	2☐	3☐	85.
*	86.	STD: WALKS UP 4 STEPS, ALTERNATING FEET	0☐	1☐	2☐	3☐	86.
*	87.	STD: WALKS DOWN 4 STEPS, ALTERNATING FEET	0☐	1☐	2☐	3☐	87.
*	88.	STD ON 15cm (6") STEP: JUMPS OFF, BOTH FEET SIMULTANEOUSLY	0☐	1☐	2☐	3☐	88.

TOTAL DIMENSION E ☐

Was this assessment indicative of this child's "regular" performance? YES ☐ NO ☐
COMMENTS:

GMFM-88 SUMMARY SCORE

DIMENSION	CALCULATION OF DIMENSION % SCORES	GOAL AREA (indicated with ✓ check)
A. Lying & Rolling	$\frac{\text{Total Dimension A}}{51} = \frac{\quad}{51} \times 100 = \quad\%$	A. ☐
B. Sitting	$\frac{\text{Total Dimension B}}{60} = \frac{\quad}{60} \times 100 = \quad\%$	B. ☐
C. Crawling & Kneeling	$\frac{\text{Total Dimension C}}{42} = \frac{\quad}{42} \times 100 = \quad\%$	C. ☐
D. Standing	$\frac{\text{Total Dimension D}}{39} = \frac{\quad}{39} \times 100 = \quad\%$	D. ☐
E. Walking, Running & Jumping	$\frac{\text{Total Dimension E}}{72} = \frac{\quad}{72} \times 100 = \quad\%$	E. ☐

TOTAL SCORE = $\frac{\%A + \%B + \%C + \%D + \%E}{\text{Total \# of Dimensions}}$

$= \frac{\quad}{5} = \quad = \quad\%$

GOAL TOTAL SCORE = $\frac{\text{Sum of \%scores for each dimension identified as a goal area}}{\text{\# of Goal areas}}$

$= \quad = \quad\%$

GMFM-66 Gross Motor Ability Estimator Score [1]

GMFM-66 Score = _____ _____ to _____ 95% Confidence Intervals

previous GMFM-66 Score = _____ _____ to _____ 95% Confidence Intervals

change in GMFM-66 = _____

[1] from the Gross Motor Ability Estimator (GMAE-2) Software

TESTING WITH AIDS/ORTHOSES USING THE GMFM-88

Indicate below with a check (4) which aid/orthosis was used and what dimension it was first applied. (There may be more than one).

AID		Dimension	Orthosis		Dimension
Rollator/pusher	☐		Hip Control	☐	
Walker	☐		Knee Control	☐	
H Frame crutches	☐		Ankle-foot Control	☐	
Crutches	☐		Foot Control	☐	
Quad Cane	☐		Shoes	☐	
Cane	☐		None	☐	
None	☐		Other	☐	
Other	☐		_____ (please specify)		

_____ (please specify)

GMFM-88 SUMMARY SCORE USING AIDS/ORTHOSES

DIMENSION	CALCULATION OF DIMENSION % SCORES				GOAL AREA (indicated with ✓ check)
F. Lying & Rolling	Total Dimension A / 51	= _____ / 51	× 100 = _____	%	A. ☐
G. Sitting	Total Dimension B / 60	= _____ / 60	× 100 = _____	%	B. ☐
H. Crawling & Kneeling	Total Dimension C / 42	= _____ / 42	× 100 = _____	%	C. ☐
I. Standing	Total Dimension D / 39	= _____ / 39	× 100 = _____	%	D. ☐
J. Walking, Running & Jumping	Total Dimension E / 72	= _____ / 72	× 100 = _____	%	E. ☐

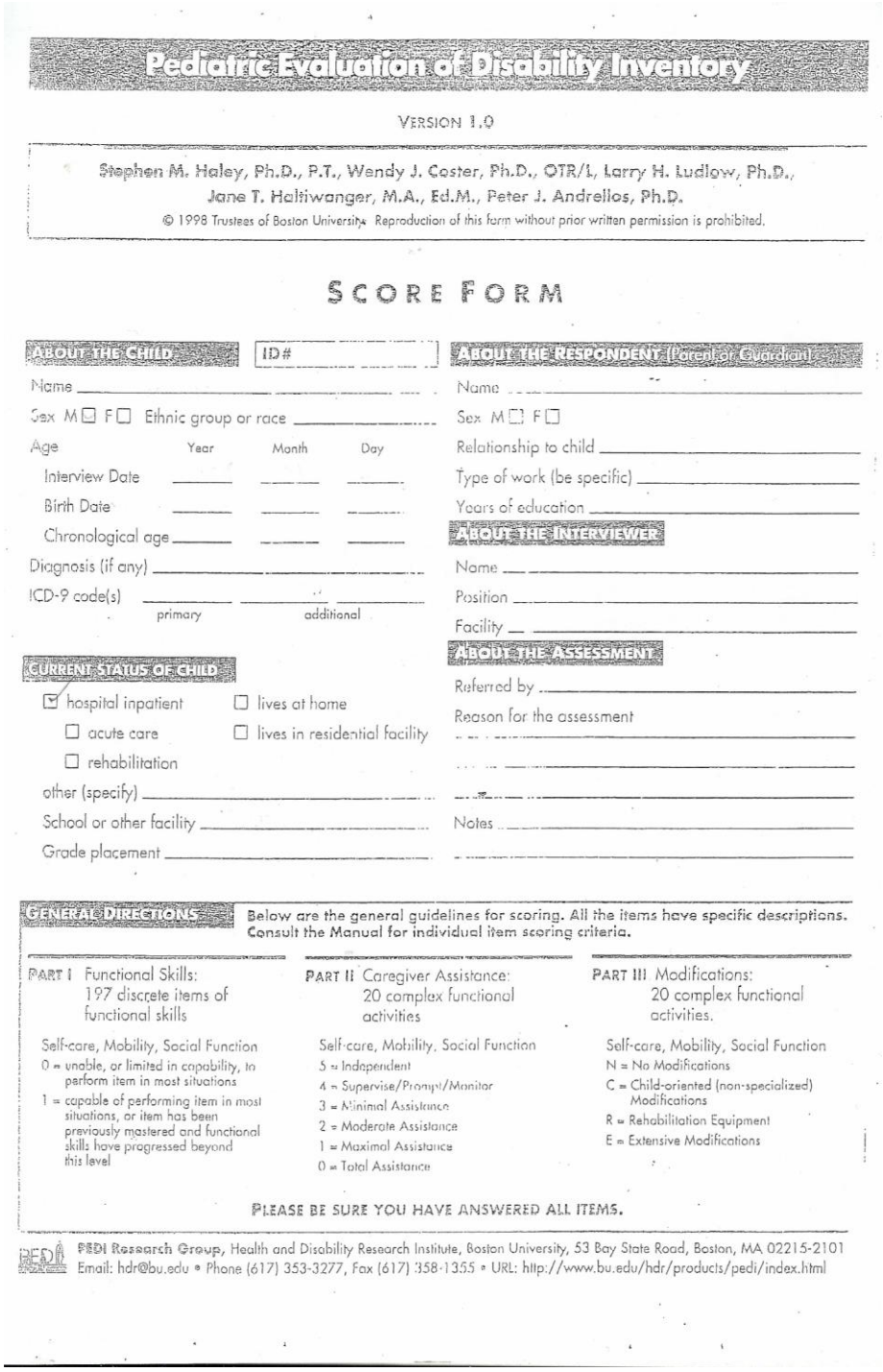
TOTAL SCORE = (%A + %B + %C + %D + %E) / Total # of Dimensions

= _____ / 5 = _____ = _____ %

GOAL TOTAL SCORE = Sum of %scores for each dimension identified as a goal area / # of Goal areas

= _____ = _____ %

Peaditric Evaluation of Disability Inventory



Pediatric Evaluation of Disability Inventory

VERSION 1.0

Stephen M. Haley, Ph.D., P.T., Wendy J. Coster, Ph.D., OTR/L, Larry H. Ludlow, Ph.D.,
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SCORE FORM

ABOUT THE CHILD ID#

Name _____

Sex M☐ F☐ Ethnic group or race _____

Age Year Month Day

Interview Date _____ _____ _____

Birth Date _____ _____ _____

Chronological age _____ _____ _____

Diagnosis (if any) _____

ICD-9 code(s) _____ _____ _____
primary additional

CURRENT STATUS OF CHILD

☑ hospital inpatient ☐ lives at home
☐ acute care ☐ lives in residential facility
☐ rehabilitation

other (specify) _____

School or other facility _____

Grade placement _____

ABOUT THE RESPONDENT (Parent or Guardian)

Name _____

Sex M☐ F☐

Relationship to child _____

Type of work (be specific) _____

Years of education _____

ABOUT THE INTERVIEWER

Name _____

Position _____

Facility _____

ABOUT THE ASSESSMENT

Referred by _____

Reason for the assessment _____

_____

_____

Notes _____

_____

GENERAL DIRECTIONS Below are the general guidelines for scoring. All the items have specific descriptions. Consult the Manual for individual item scoring criteria.

PART I Functional Skills: 197 discrete items of functional skills

Self-care, Mobility, Social Function
0 = unable, or limited in capability, to perform item in most situations
1 = capable of performing item in most situations, or item has been previously mastered and functional skills have progressed beyond this level

PART II Caregiver Assistance: 20 complex functional activities

Self-care, Mobility, Social Function
5 = Independent
4 = Supervise/Prompt/Monitor
3 = Minimal Assistance
2 = Moderate Assistance
1 = Maximal Assistance
0 = Total Assistance

PART III Modifications: 20 complex functional activities.

Self-care, Mobility, Social Function
N = No Modifications
C = Child-oriented (non-specialized) Modifications
R = Rehabilitation Equipment
E = Extensive Modifications

PLEASE BE SURE YOU HAVE ANSWERED ALL ITEMS.

PEDI Research Group, Health and Disability Research Institute, Boston University, 53 Bay State Road, Boston, MA 02215-2101
Email: hdr@bu.edu • Phone (617) 353-3277, Fax (617) 358-1355 • URL: http://www.bu.edu/hdr/products/pedi/index.html

Part I: Functional Skills

SELF-CARE DOMAIN Place a check corresponding to each item:
Item scores: 0 = unable; 1 = capable

A. Food Textures

		UNABLE 0	CAPABLE 1
1.	Eats pureed/blended/strained foods		
2.	Eats ground/lumpy foods		
3.	Eats cut up/chunky/diced foods		
4.	Eats all textures of table food		

B. Use of Utensils

		0	1
5.	Finger feeds		
6.	Scoops with a spoon and brings to mouth		
7.	Uses a spoon well		
8.	Uses a fork well		
9.	Uses a knife to butter bread, cut soft foods		

C. Use of Drinking Containers

		0	1
10.	Holds bottle or spout cup		
11.	Lifts cup to drink, but cup may tip		
12.	Lifts open cup securely with two hands		
13.	Lifts open cup securely with one hand		
14.	Pours liquid from carton or pitcher		

D. Toothbrushing

		0	1
15.	Opens mouth for teeth to be brushed		
16.	Holds toothbrush		
17.	Brushes teeth; but not a thorough job		
18.	Thoroughly brushes teeth		
19.	Prepares toothbrush with toothpaste		

E. Hairbrushing

		0	1
20.	Holds head in position while hair is combed		
21.	Brings brush or comb to hair		
22.	Brushes or combs hair		
23.	Manages tangles and parts hair		

F. Nose Care

		0	1
24.	Allows nose to be wiped		
25.	Blows nose into held tissue		
26.	Wipes nose using tissue on request		
27.	Wipes nose using tissue without request		
28.	Blows and wipes nose without request		

G. Handwashing

		0	1
29.	Holds hands out to be washed		
30.	Rubs hands together to clean		
31.	Turns water on and off, obtains soap		
32.	Washes hands thoroughly		
33.	Dries hands thoroughly		

H. Washing Body & Face

		0	1
34.	Tries to wash parts of body		
35.	Washes body thoroughly, not including face		
36.	Obtains soap (and soaps washcloth, if used)		
37.	Dries body thoroughly		
38.	Washes and dries face thoroughly		

I. Pullover/Front-Opening Garments

		0	1
39.	Assists, such as pushing arms through shirt		
40.	Removes T-shirt, dress or sweater (pullover garment without fasteners)		
41.	Puts on T-shirt, dress or sweater		
42.	Puts on and removes front-opening shirt, not including fasteners		
43.	Puts on and removes front-opening shirt, including fasteners		

J. Fasteners

		UNABLE 0	CAPABLE 1
44.	Tries to assist with fasteners		
45.	Zips and unzips, doesn't separate or hook zipper		
46.	Snaps and unsnaps		
47.	Buttons and unbuttons		
48.	Zips and unzips, separates and hooks zipper		

K. Pants

		0	1
49.	Assists, such as pushing legs through pants		
50.	Removes pants with elastic waist		
51.	Puts on pants with elastic waist		
52.	Removes pants, including unfastening		
53.	Puts on pants, including fastening		

L. Shoes/Socks

		0	1
54.	Removes socks and unfastened shoes		
55.	Puts on unfastened shoes		
56.	Puts on socks		
57.	Puts shoes on correct feet; manages velcro fasteners		
58.	Ties shoelaces		

M. Toileting Tasks (clothes, toilet management, and wiping only)

		0	1
59.	Assists with clothing management		
60.	Tries to wipe self after toileting		
61.	Manages toilet seat, gets toilet paper and flushes toilet		
62.	Manages clothes before and after toileting		
63.	Wipes self thoroughly after bowel movements		

N. Management of Bladder (Score = 1 if child has previously mastered skill)

		0	1
64.	Indicates when wet in diapers or training pants		✓
65.	Occasionally indicates need to urinate (daytime)		
66.	Consistently indicates need to urinate with time to get to toilet (daytime)		
67.	Takes self into bathroom to urinate (daytime)		
68.	Consistently stays dry day and night		

O. Management of Bowel (Score = 1 if child has previously mastered skill)

		0	1
69.	Indicates need to be changed		
70.	Occasionally indicates need to use toilet (daytime)		
71.	Consistently indicates need to use toilet with time to get to toilet (daytime)		
72.	Distinguishes between need for urination and bowel movements		
73.	Takes self into bathroom for bowel movements, has no bowel accidents		

SELF-CARE DOMAIN SUM ____

PLEASE BE SURE YOU HAVE ANSWERED ALL ITEMS.

Comments

MOBILITY DOMAIN

Place a check corresponding to each item:
Item scores: 0 = unable; 1 = capable

A. Toilet Transfers

	UNABLE 0	CAPABLE 1
1. Sits if supported by equipment or caregiver		
2. Sits unsupported on toilet or potty chair		
3. Gets on and off low toilet or potty		
4. Gets on and off adult-sized toilet		
5. Gets on and off toilet, not needing own arms		

B. Chair/Wheelchair Transfers

	0	1
6. Sits if supported by equipment or caregiver		
7. Sits unsupported on chair or bench		
8. Gets on and off low chair or furniture		
9. Gets in and out of adult-sized chair/wheelchair		
10. Gets in and out of chair, not needing own arms		

C. Car Transfers

	0	1
11. Moves in car; scoots on seat or gets in and out of car seat		
12. Gets in and out of car with little assistance or instruction		
13. Gets in and out of car with no assistance or instruction		
14. Manages seat belt or chair restraint		
15. Gets in and out of car and opens and closes car door		

D. Bed Mobility/Transfers

	0	1
16. Raises to sitting position in bed or crib		
17. Comes to sit at edge of bed; lies down from sitting at edge of bed		
18. Gets in and out of own bed		
19. Gets in and out of own bed, not needing own arms		

E. Tub Transfers

	0	1
20. Sits if supported by equipment or caregiver in a tub or sink		
21. Sits unsupported and moves in tub		
22. Climbs or scoots in and out of tub		
23. Sits down and stands up from inside tub		
24. Steps/transfers into and out of an adult-sized tub		

F. Indoor Locomotion Methods (Score = 1 if mastered)

	0	1
25. Rolls, scoots, crawls, or creeps on floor		
26. Walks, but holds onto furniture, walls, caregivers or uses devices for support		
27. Walks without support		

G. Indoor Locomotion: Distance/Speed (Score = 1 if mastered)

	0	1
28. Moves within a room but with difficulty (falls; slow for age)		
29. Moves within a room with no difficulty		
30. Moves between rooms but with difficulty (falls; slow for age)		
31. Moves between rooms with no difficulty		
32. Moves indoors 50 feet; opens and closes inside and outside doors		

H. Indoor Locomotion: Pulls/Carries Objects

	0	1
33. Changes physical location purposefully		
34. Moves objects along floor		
35. Carries objects small enough to be held in one hand		
36. Carries objects large enough to require two hands		
37. Carries fragile or spillable objects		

I. Outdoor Locomotion: Methods

	UNABLE 0	CAPABLE 1
38. Walks, but holds onto objects, caregiver, or devices for support		
39. Walks without support		

J. Outdoor Locomotion: Distance/Speed (Score = 1 if mastered)

	0	1
40. Moves 10-50 feet (1-5 car lengths)		
41. Moves 50-100 feet (5-10 car lengths)		
42. Moves 100-150 feet (35-50 yards)		
43. Moves 150 feet and longer, but with difficulty (stumbles; slow for age)		
44. Moves 150 feet and longer with no difficulty		

K. Outdoor Locomotion: Surfaces

	0	1
45. Level surfaces (smooth sidewalks, driveways)		
46. Slightly uneven surfaces (cracked pavement)		
47. Rough, uneven surfaces (lawns, gravel driveway)		
48. Up and down incline or ramps		
49. Up and down curbs		

L. Upstairs (Score = 1 if child has previously mastered skill)

	0	1
50. Scoots or crawls up partial flight (1-11 steps)		
51. Scoots or crawls up full flight (12-15 steps)		
52. Walks up partial flight		
53. Walks up full flight, but with difficulty (slow for age)		
54. Walks up entire flight with no difficulty		

M. Downstairs (Score = 1 if child has previously mastered skill)

	0	1
55. Scoots or crawls down partial flight (1-11 steps)		
56. Scoots or crawls down full flight (12-15 steps)		
57. Walks down partial flight		
58. Walks down full flight, but with difficulty (slow for age)		
59. Walks down full flight with no difficulty		

MOBILITY DOMAIN SUM

PLEASE BE SURE YOU HAVE ANSWERED ALL ITEMS.

SOCIAL FUNCTION DOMAIN

Place a check corresponding to each item: Item scores: 0 = unable; 1 = capable

A. Comprehension Word Meanings

	0	1
1. Orients to sound		
2. Responds to "no"; recognizes own name or that of familiar people		
3. Understands 10 words		
4. Understands when you talk about relationships among people and/or things that are visible		
5. Understands when you talk about time and sequence of events		

B. Comprehension of Sentence Complexity

	0	1
6. Understands short sentences about familiar objects and people		
7. Understands 1-step commands with words that describe people or things		
8. Understands directions that describe where something is		
9. Understands 2-step commands, using if/then, before/after, first/second, etc.		
10. Understands two sentences that are about the same subject but have a different form		

Parts II and III: Caregiver Assistance and Modification

Circle the appropriate score for Caregiver Assistance and Modification for each item.

	Caregiver Assistance Scale						Modification Scale			
	Independent	Supervision	Minimal	Moderate	Maximal	Total	None	Child	Rehab	Extensive
SELF-CARE DOMAIN	5	4	3	2	1	0	N	C	R	E
A. **Eating**: eating and drinking regular meal; do not include cutting steak, opening containers or serving food from serving dishes	5	4	3	2	1	0	N	C	R	E
B. **Grooming**: brushing teeth, brushing or combing hair and caring for nose	5	4	3	2	1	0	N	C	R	E
C. **Bathing**: washing and drying face and hands, taking a bath or shower; do not include getting in and out of a tub or shower, water preparation, or washing back or hair	5	4	3	2	1	0	N	C	R	E
D. **Dressing Upper Body**: all indoor clothes, not including back fasteners; include help putting on or taking off splint or artificial limb; do not include getting clothes from closet or drawers	5	4	3	2	1	0	N	C	R	E
E. **Dressing Lower Body**: all indoor clothes; include putting on or taking off brace or artificial limb; do not include getting clothes from closet or drawers	5	4	3	2	1	0	N	C	R	E
F. **Toileting**: clothes, toilet management or external device use, and hygiene; do not include toilet transfers, monitoring schedule, or cleaning up after accidents	5	4	3	2	1	0	N	C	R	E
G. **Bladder Management**: control of bladder day and night, clean-up after accidents, monitoring schedule	5	4	3	2	1	0	N	C	R	E
H. **Bowel Management**: control of bowel day and night, clean-up after accidents, monitoring schedule	5	4	3	2	1	0	N	C	R	E
Self-Care Totals	SELF-CARE SUM ☐									
MOBILITY DOMAIN										
A. **Chair/Toilet Transfers**: child's wheelchair, adult-sized chair, adult-sized toilet	5	4	3	2	1	0	N	C	R	E
B. **Car Transfers**: mobility within car/van, seat belt use, transfers, and opening and closing doors	5	4	3	2	1	0	N	C	R	E
C. **Bed Mobility/Transfers**: getting in and out and changing positions in child's own bed	5	4	3	2	1	0	N	C	R	E
D. **Tub Transfers**: getting in and out of adult-sized tub	5	4	3	2	1	0	N	C	R	E
E. **Indoor Locomotion**: 50 feet (3-4 rooms); do not include opening doors or carrying objects	5	4	3	2	1	0	N	C	R	E
F. **Outdoor Locomotion**: 150 feet (15 car lengths) on level surfaces; focus on physical ability to move outdoors (do not consider compliance or safety issues such as crossing streets)	5	4	3	2	1	0	N	C	R	E
G. **Stairs**: climb and descend a full flight of stairs (12-15 steps)	5	4	3	2	1	0	N	C	R	E
Mobility Totals	MOBILITY SUM ☐									
SOCIAL FUNCTION DOMAIN										
A. **Functional Comprehension**: understanding of requests and instructions	5	4	3	2	1	0	N	C	R	E
B. **Functional Expression**: ability to provide information about own activities and make own needs known; include clarity of articulation	5	4	3	2	1	0	N	C	R	E
C. **Joint Problem Solving**: include communication of problem and working with caregiver or other adult to find a solution; include only ordinary problems occurring during daily activities; (for example, lost toy; conflict over clothing choices.)	5	4	3	2	1	0	N	C	R	E
D. **Peer Play**: ability to plan and carry out joint activities with a familiar peer	5	4	3	2	1	0	N	C	R	E
E. **Safety**: caution in routine daily safety situations, including stairs, sharp or hot objects and traffic	5	4	3	2	1	0	N	C	R	E
Social Function Totals	SOCIAL FUNCTION SUM ☐									

Self-Care Modification Frequencies

Mobility Modification Frequencies

Social Function Modification Frequencies

Pediatric Evaluation of Disability Inventory

VERSION 1.0

Name _____ Test Date _____ Age _____

ID# _____ Respondent/Interviewer _____

SCORE SUMMARY

Composite Scores

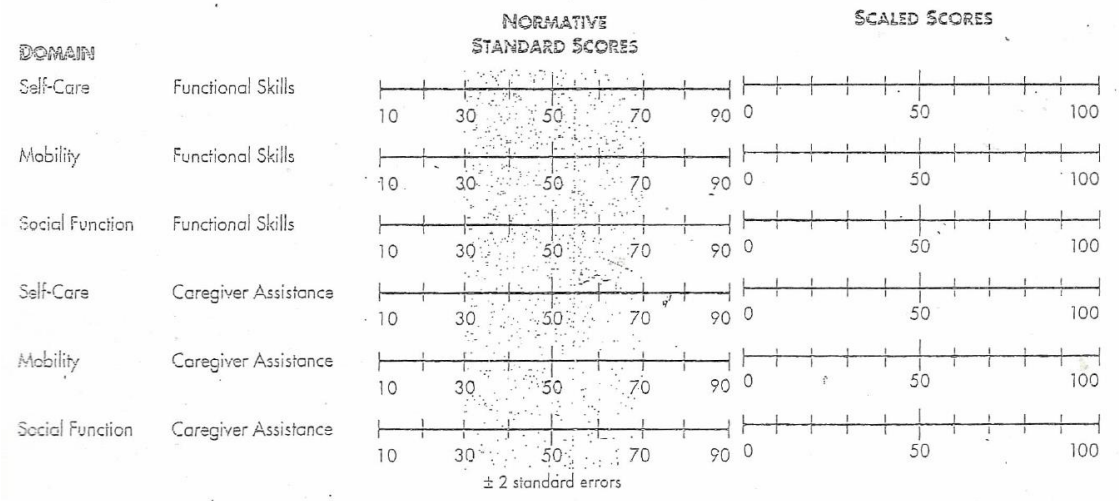
DOMAIN		RAW SCORE	NORMATIVE STANDARD SCORE	STANDARD ERROR	SCALED SCORE	STANDARD ERROR	*FIT SCORE*
Self-Care	Functional Skills						
Mobility	Functional Skills						
Social Function	Functional Skills						
Self-Care	Caregiver Assistance						
Mobility	Caregiver Assistance						
Social Function	Caregiver Assistance						

*Obtainable only through use of software program

MODIFICATION FREQUENCIES

SELF-CARE (8 ITEMS)				MOBILITY (7 ITEMS)				SOCIAL FUNCTION (5 ITEMS)			
None	Child	Rehab	Extensive	None	Child	Rehab	Extensive	None	Child	Rehab	Extensive

Score Profile



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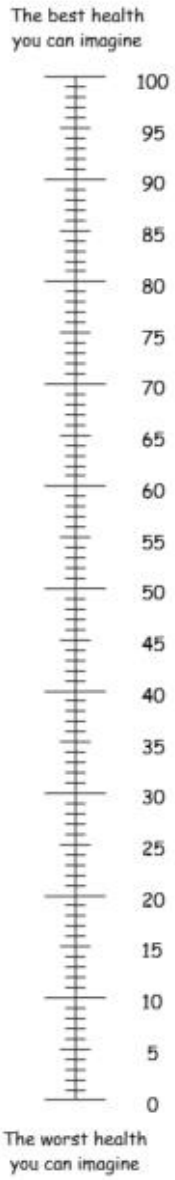
EQ-5-DYY

Describing the child's health TODAY →	
Under each heading, please tick the ONE box that **you think** best describes the child's health **TODAY**.	
MOBILITY *(walking about)* →	
He/she has no problems walking about	❑
He/she has some problems walking about	❑
He/she has a lot of problems walking about	❑
LOOKING AFTER HIM/HERSELF	
He/she has no problems washing or dressing him/herself	❑
He/she has some problems washing or dressing him/herself	❑
He/she has a lot of problems washing or dressing him/herself	❑
DOING USUAL ACTIVITIES *(for example: going to school, hobbies, sports, playing, doing things with family or friends)*	
He/she has no problems doing his/her usual activities	❑
He/she has some problems doing his/her usual activities	❑
He/she has a lot of problems doing his/her usual activities	❑
HAVING PAIN OR DISCOMFORT	
He/she has no pain or discomfort	❑
He/she has some pain or discomfort	❑
He/she has a lot of pain or discomfort	❑
FEELING WORRIED, SAD OR UNHAPPY	
He/she is not worried, sad or unhappy	❑
He/she is a bit worried, sad or unhappy	❑
He/she is very worried, sad or unhappy	❑

2

The child's health TODAY

- We would like to know how good or bad you think the child's health is TODAY.
- This line is numbered 0 to 100.
- 100 means the best health you can imagine.
  0 means the worst health you can imagine.
- Please mark an X on the line to show how good or bad **you think** the child's health is **TODAY**.



Care-giver Strain Index

Caregiver Strain Index (CSI)

I am going to read a list of things that other people have found to be difficult. ***Would you tell me whether any of these apply to you?*** (GIVE EXAMPLES)

	Yes = 1	No = 0
Sleep is disturbed (e.g., because . . . is in and out of bed or wanders around at night)		
It is inconvenient (e.g., because helping takes so much time or it's a long drive over to help)		
It is a physical strain (e.g., because of lifting in and out of a chair; effort or concentration is required)		
It is confining (e.g., helping restricts free time or cannot go visiting)		
There have been family adjustments (e.g., because helping has disrupted routine; there has been no privacy)		
There have been changes in personal plans (e.g., had to turn down a job; could not go on vacation)		
There have been emotional adjustments (e.g., because of severe arguments)		
Some behavior is upsetting (e.g., because of incontinence; . . . has trouble remembering things; or . . . accuses people of taking things)		
It is upsetting to find . . . has changed so much from his/her former self (e.g., he/she is a different person than he/she used to be)		
There have been work adjustments (e.g., because of having to take time off)		
It is a financial strain		
Feeling completely overwhelmed (e.g., because of worry about . . . ; concerns about how you will manage)		
Total Score (Count yes responses. Any positive answer may indicate a need for intervention in that area. A score of 7 or higher indicates a high level of stress.)		

cited as the source. Available on the internet at www.hartfordign.org. E-mail notification of usage to: hartford.ign@nyu.edu.

Appendix 8: Raw PEDI scores

6.4.1 Mobility

Mobility	Child	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17
Baseline Toilet transfers	Sits if supported by equipment or caregiver	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	0	1
	Sits unsupported on toilet or potty chair	1	1	1	0	1	1	1	1	1	0	1	1	1	0	1	0	1
	Gets on and off low toilet or potty	1	1	0	0	1	1	0	1	1	0	1	1	1	0	1	0	1
	Gets on and off adult size toilet	1	1	0	0	1	1	0	1	1	0	0	1	1	0	1	0	1
	Gets on and off toilet not needing own arms	0	1	0	0	1	0	0	1	1	0	0	0	0	0	0	0	1
Chair or wheelchair transfers	Sits if supported by equipment or caregiver	1	1	1	0	1	1	1	1	1	1	1	1	1	1	1	1	1
	Sits unsupported on chair or bench	1	1	1	0	1	1	1	1	1	0	1	1	1	0	1	0	1
	Gets on and off low chair or furniture	1	1	0	0	1	1	0	1	1	0	1	1	1	0	1	0	1
	Gets on and off adult size chair or wheelchair	1	1	0	0	1	1	0	1	1	0	1	1	1	0	1	0	1
	Gets in and out of chair, not needing arms	0	1	0	0	1	0	0	1	1	0	0	0	0	0	0	0	1
Car transfers	Moves in car, scoots on seat or gets in and out of car seat	1	1	1	0	1	1	0	1	1	0	0	1	1	0	1	0	1
	Gets in and out of car with little assistance or instruction	0	1	0	0	1	0	0	1	1	0	0	1	1	0	1	0	1
	Gets in and out of car with no assistance or instruction	0	1	0	0	1	0	0	1	1	0	0	1	1	0	1	0	1
	Manages seatbelt or chair restraint	0	1	0	0	1	0	0	1	1	0	0	0	0	0	0	0	1
	Gets in and out of car and opens and closes car door	0	1	0	0	1	0	0	1	1	0	0	0	0	0	0	0	1
Bed mobility or transfers	Raises to sitting position in bed or crib	1	1	1	0	1	1	1	1	1	0	1	1	1	0	1	0	1
	Comes to sit on edge of bed, lies down from sitting at edge of bed	1	1	0	0	1	1	1	1	1	0	1	1	1	0	1	0	1
	Gets in and out of own bed,	1	1	0	0	1	0	0	1	1	0	1	1	1	0	1	0	1
	Gets in and out of own bed, not needing own arms	1	1	0	0	1	0	0	1	1	0	0	0	1	0	0	0	1
Tub transfers	Sits if supported by equipment or caregiver in a tub or sink	1	1	0	1	1	1	0	1	1	0	1	1	1	0	1	1	1
	Sits unsupported and	0	1	0	0	1	1	0	1	1	0	1	1	0	0	1	0	1

	moves in tub																	
	Climbs and scoots in and out of tub	0	0	0	0	1	0	0	1	1	0	0	1	0	0	1	0	1
	Sits down and stand up from inside tub	0	0	0	0	1	0	0	1	1	0	0	1	0	0	1	0	1
	Steps or transfers into and out of adult sized tub	0	0	0	0	1	0	0	1	1	0	0	0	0	0	1	0	1
Indoor locomotion methods	Rolls, scoots, crawls or creeps on floor	1	1	1	0	1	1	1	1	1	1	1	1	1	0	1	1	1
	Walks, but holds onto furniture, walls, caregivers or uses a device for support	1	1	0	0	1	1	0	1	1	0	1	1	1	0	1	0	1
	Walks without support	0	1	0	0	1	1	0	1	1	0	1	1	1	0	1	0	1
Indoor locomotion distance or speed	Moves within a room but with difficulty falls or slow for age	1	1	0	0	1	1	0	1	1	0	1	1	1	0	1	0	1
	Moves within room with no difficulty	0	1	0	0	1	0	0	1	1	0	1	1	1	0	1	0	1
	Moves between rooms but with difficulty falls or slow for age	1	1	0	0	1	1	0	1	1	0	1	1	1	0	1	0	1
	Moves between rooms with no difficulty	0	1	0	0	1	0	0	1	1	0	0	1	1	0	0	0	1
	Moves indoors 50 feet, opens and closes inside and outside doors	0	1	0	0	1	0	0	1	1	0	0	0	1	0	0	0	1
Indoor locomotion pulls or carries objects	Changes physical location purposely	1	1	0	0	1	1	0	1	1	0	1	1	1	0	1	1	1
	Moves objects along floor	1	1	0	0	1	1	0	1	1	0	1	1	1	0	1	0	1
	Carries objects small enough to be held in one hand	1	1	0	0	1	1	0	1	1	0	1	1	1	0	1	0	1
	Carries object large enough to require two hands	0	1	0	0	1	1	0	1	1	0	0	1	1	0	1	0	1
	Carries fragile or spillable objects	0	1	0	0	0	0	0	1	1	0	0	1	0	0	0	0	1
Outdoor locomotion	Walks but holds onto objects, caregiver or device for support	1	1	0	0	1	1	0	1	1	0	1	0	1	0	1	0	1
	Walks without support	1	1	0	0	1	0	0	1	1	0	1	1	1	0	1	0	1
Outdoor locomotion distance and speed	Moves 10 to 50 feet (1 to 5 car lengths)	1	1	0	0	1	0	0	1	1	0	1	1	1	0	1	0	1
	Moves 50 to 100 feet (1 to 10 car lengths)	1	1	0	0	1	0	0	1	1	0	0	1	1	0	1	0	1
	Moves 100 to 150 feet (35 to 50 yards)	0	1	0	0	1	0	0	1	1	0	0	1	1	0	1	0	1
	Moves 150 feet and longer but with difficulty (stumbles slow for age	0	1	0	0	1	0	0	1	1	0	0	1	1	0	1	0	1
	Moves 150 feet and longer with no difficulty	0	1	0	0	1	0	0	1	1	0	0	1	1	0	0	0	1
Outdoor	Level surfaces	1	1	0	0	1	1	0	1	1	0	1	1	1	0	1	0	1

locomotion surfaces	(sidewalks, driveways																	
	Slightly uneven surfaces (cracked pavement)	0	1	0	0	1	1	0	1	1	0	0	1	1	0	1	0	1
	Rough, uneven surfaces (lawns, gravel)	0	0	0	0	1	1	0	1	1	0	0	1	1	0	1	0	1
	Up and down an incline or ramps	0	0	0	0	0	0	0	1	1	0	0	1	1	0	0	0	1
	Up and down curbs	0	0	0	0	0	0	0	1	1	0	0	1	1	0	0	0	1
Upstairs	Scoots or crawls up partial flight 1 to 11 steps	1	1	0	0	1	1	0	1	1	0	1	1	1	0	1	0	1
	Scoots and crawls up full flight (12 to 15 steps)	0	1	0	0	1	1	0	1	1	0	0	1	1	0	1	0	1
	Walks up partial flight	1	1	0	0	1	1	0	1	1	0	1	1	1	0	1	0	1
	Walks up full flight, but with difficulty (slow for age)	0	1	0	0	0	1	0	1	1	0	0	0	0	0	0	0	1
	Walks up entire flight with no difficulty	0	0	0	0	0	0	0	1	1	0	0	0	0	0	0	0	1
Downstairs	Scoots or crawls down partial flight (1to 11 steps)	1	1	0	0	1	1	0	1	1	0	1	1	1	0	1	0	1
	Scoots or crawls down full flight of stairs (12 to 15 steps	0	1	0	0	1	1	0	1	1	0	0	1	1	0	1	0	1
	Walks down partial flight	0	1	0	0	1	1	0	1	1	0	1	1	1	0	1	0	1
	Walks down full flight, but with difficulty (slow for age)	0	1	0	0	0	0	0	1	1	0	0	0	0	0	0	0	1
	Walks down full flight with no difficulty	0	0	0	0	0	0	0	1	1	1	0	0	0	0	0	0	1
Week 3 Toilet transfers	Sits if supported by equipment or caregiver 1	1	1	1	0	1	1		1	1	1	1	1		1	1	0	1
	Sits unsupported on toilet or potty chair	1	1	1	0	1	1		1	1	1	1	1		0	1	0	1
	Gets on and off low toilet or potty	1	1	0	0	1	1		1	1	1	1	1		0	1	0	1
	Gets on and off adult size toilet	1	1	0	0	1	1		1	1	0	1	0		0	1	0	1
	Gets on and off toilet not needing own arms	1	1	0	0	1	1		1	1	0	1	0		0	1	0	1
Chair or wheelchair transfers	Sits if supported by equipment or caregiver	1	1	1	1	1	1		1	1	0	1	1		0	1	1	1
	Sits unsupported on chair or bench	1	1	1	0	1	1		1	1	0	1	1		1	1	0	1
	Gets on and off low chair or furniture	1	1	0	0	1	1		1	1	0	1	1		0	1	0	1
	Gets on and off adult size chair or wheelchair	1	1	0	0	1	1		1	1	0	1	0		0	1	0	1
	Gets in and out of chair, not needing arms	1	1	0	0	1	1		1	1	0	1	0		0	1	0	1
Car transfers	Moves in car, scoots on seat or gets in and out of car seat	1	1	1	0	1	1		1	1	1	1	1		0	1	0	1
	Gets in and out of car with little assistance or instruction	1	1	0	0	1	1		1	1	1	1	1		0	1	0	1
	Gets in and out of car with no assistance or	0	1	0	0	1	1		1	1	0	1	0		0	1	0	1

	instruction																		
	Manages seatbelt or chair restraint	0	1	0	0	1	0		1	1	0	0	0		0	1	0	1
	Gets in and out of car and opens and closes car door	0	1	0	0	1	0		1	1	0	1	0		0	1	0	1
Bed mobility or transfers	Raises to sitting position in bed or crib	1	1	1	0	1	1		1	1	1	0	1		0	1	0	1
	Comes to sit on edge of bed, lies down from sitting at edge of bed	1	1	1	0	1	1		1	1	1	1	1		0	1	0	1
	Gets in and out of own bed,	1	1	1	0	1	1		1	1	1	1	1		0	1	0	1
	Gets in and out of own bed, not needing own arms	1	1	0	0	1	1		1	1	0	1	0		0	1	0	1
Tub transfers	Sits if supported by equipment or caregiver in a tub or sink	1	1	0	0	1	1		1	1	1	1	1		0	1	1	1
	Sits unsupported and moves in tub	1	1	0	0	1	1		1	1	0	0	1		0	1	0	1
	Climbs and scoots in and out of tub	0	1	0	0	1	1		1	1	0	0	1		0	1	0	1
	Sits down and stand up from inside tub	0	1	0	0	1	0		1	1	0	0	1		0	1	0	1
	Steps or transfers into and out of adult sized tub	0	1	0	0	1	0		1	1	0	1	0		0	1	0	1
Indoor locomotion methods	Rolls, scoots, crawls or creeps on floor	1	1	1	1	1	1		1	1	1	1	1		1	1	1	1
	Walks, but holds onto furniture, walls, caregivers or uses a device for support	1	1	1	0	1	1		1	1	1	1	1		0	1	0	1
	Walks without support	1	1	0	0	1	1		1	1	1	1	1		0	1	0	1
Indoor locomotion distance or speed	Moves within a room but with difficulty falls or slow for age	1	1	1	0	1	1		1	1	1	1	1		0	1	0	1
	Moves within room with no difficulty	1	1	1	0	1	1		1	1	1	1	1		0	1	0	1
	Moves between rooms but with difficulty falls or slow for age	1	1	0	0	1	1		1	1	1	1	1		0	1	0	1
	Moves between rooms with no difficulty	1	1	0	0	1	1		1	1	0	1	1		0	1	0	1
	Moves indoors 50 feet, opens and closes inside and outside doors	1	1	0	0	1	0		1	1	0	1	1		0	1	0	1
Indoor locomotion pulls or carries objects	Changes physical location purposely	1	1	1	0	1	1		1	1	1	1	1		0	1	1	1
	Moves objects along floor	1	1	1	0	1	1		1	1	1	1	1		0	1	0	1
	Carries objects small enough to be held in one hand	1	1	1	0	1	1		1	1	1	1	1		0	1	0	1
	Carries object large enough to require two hands	1	1	1	0	1	1		1	1	0	1	1		0	1	0	1

	Carries fragile or spillable objects	0	1	0	0	1	0		1	1	0	1	0		0	0	0	1
Outdoor locomotion	Walks but holds onto objects, caregiver or device for support	1	1	1	0	1	1		1	1	1	1	1		0	1	0	1
	Walks without support	1	1	1	0	1	1		1	1	1	1	1		0	1	0	1
Outdoor locomotion distance and speed	Moves 10 to 50 feet (1 to 5 car lengths)	1	1	1	0	1	1		1	1	0	1	1		0	1	0	1
	Moves 50 to 100 feet (1 to 10 car lengths)	1	1	0	0	1	1		1	1	0	1	1		0	1	0	1
	Moves 100 to 150 feet (35 to 50 yards)	1	1	0	0	1	1		1	1	0	1	1		0	1	0	1
	Moves 150 feet and longer but with difficulty (stumbles slow for age	1	1	0	0	1	1		1	1	0	1	1		0	1	0	1
	Moves 150 feet and longer with no difficulty	0	1	0	0	0	1		1	1	0	1	1		0	0	0	1
Outdoor locomotion surfaces	Level surfaces (sidewalks, driveways	1	1	1	0	1	1		1	1	0	1	1		0	1	0	1
	Slightly uneven surfaces (cracked pavement)	1	1	1	0	1	1		1	1	0	1	1		0	1	0	1
	Rough, uneven surfaces (lawns, gravel)	1	1	0	0	1	1		1	1	0	1	1		0	1	0	1
	Up and down an incline or ramps	0	1	0	0	1	1		1	1	0	1	1		0	1	0	1
	Up and down curbs	0	1	0	0	1	1		1	1	0	1	1		0	1	0	1
Upstairs	Scoots or crawls up partial flight 1 to 11 steps	1	1	1	0	1	1		1	1	0	1	1		0	1	0	1
	Scoots and crawls up full flight (12 to 15 steps)	1	1	0	0	1	1		1	1	0	1	1		0	1	0	1
	Walks up partial flight	1	1	0	0	1	1		1	1	0	1	1		0	1	0	1
	Walks up full flight, but with difficulty (slow for age)	0	1	0	0	1	0		1	1	0	1	1		0	1	0	1
	Walks up entire flight with no difficulty	0	1	0	0	0	0		1	1	0	0	1		0	0	0	1
Downstairs	Scoots or crawls down partial flight (1to 11 steps)	1	1	0	0	1	1		1	1	0	1	1		0	1	0	1
	Scoots or crawls down full flight of stairs (12 to 15 steps	1	1	0	0	1	1		1	1	0	1	1		0	1	0	1
	Walks down partial flight	1	1	0	0	1	1		1	1	0	1	1		0	1	0	1
	Walks down full flight, but with difficulty (slow for age)	0	1	0	0	1	0		1	1	0	1	1		0	1	0	1
	Walks down full flight with no difficulty	0	1	0	0	0	0		1	1	0	0	1		0	0	0	1
Week 7 Toilet transfers	Sits if supported by equipment or caregiver 2	1	1	1	1	1		1	1		1	1	1	1	1	1	1	
	Sits unsupported on toilet or potty chair	1	1	1	0	1		0	1		1	1	1	1	0	1	0	
	Gets on and off low toilet or potty	1	1	1	0	1		0	1		1	1	1	1	0	1	0	
	Gets on and off adult size toilet	1	1	1	0	1		0	1		1	1	1	1	0	1	0	
	Gets on and off toilet	1	1	0	0	1		0	1		1	1	0	1	0	1	0	

	not needing own arms																	
Chair or wheelchair transfers	Sits if supported by equipment or caregiver	1	1	1	1	1		1	1		1	1	1	1	1	1	1	
	Sits unsupported on chair or bench	1	1	1	0	1		1	1		1	1	1	1	0	1	0	
	Gets on and off low chair or furniture	1	1	1	0	1		0	1		1	1	1	1	0	1	0	
	Gets on and off adult size chair or wheelchair	1	1	1	0	1		0	1		1	1	1	1	0	1	0	
	Gets in and out of chair, not needing arms	1	1	0	0	1		0	1		0	1	0	1	0	1	0	
Car transfers	Moves in car, scoots on seat or gets in and out of car seat	1	1	1	0	1		0	1		1	1	1	1	0	1	0	
	Gets in and out of car with little assistance or instruction	1	1	0	0	1		0	1		1	1	1	1	0	1	0	
	Gets in and out of car with no assistance or instruction	1	1	0	0	1		0	1		0	1	0	1	0	1	0	
	Manages seatbelt or chair restraint	0	1	0	0	1		0	1		0	0	0	0	0	1	0	
	Gets in and out of car and opens and closes car door	0	1	0	0	1		0	1		0	1	0	1	0	1	0	
Bed mobility or transfers	Raises to sitting position in bed or crib	1	1	1	0	1		1	1		1	1	1	1	0	1	0	
	Comes to sit on edge of bed, lies down from sitting at edge of bed	1	1	1	0	1		0	1		1	1	1	1	0	1	0	
	Gets in and out of own bed,	1	1	0	0	1		0	1		1	1	1	1	0	1	0	
	Gets in and out of own bed, not needing own arms	1	1	0	0	1		0	1		0	1	0	1	0	1	0	
Tub transfers	Sits if supported by equipment or caregiver in a tub or sink	1	1	1	1	1		0	1		0	1	1	1	0	1	1	
	Sits unsupported and moves in tub	1	1	1	0	1		0	1		0	1	1	1	0	1	0	
	Climbs and scoots in and out of tub	1	1	0	0	1		0	1		0	1	1	1	0	1	0	
	Sits down and stand up from inside tub	0	1	0	0	1		0	1		0	1	1	1	0	1	0	
	Steps or transfers into and out of adult sized tub	0	1	0	0	1		0	1		0	1	0	0	0	1	0	
Indoor locomotion methods	Rolls, scoots, crawls or creeps on floor	1	1	1	1	1		1	1		0	1	1	1	1	1	1	
	Walks, but holds onto furniture, walls, caregivers or uses a device for support	1	1	1	0	1		0	1		1	1	1	1	0	1	0	
	Walks without support	1	1	1	0	1		0	1		1	1	1	1	0	1	0	
Indoor locomotion distance or speed	Moves within a room but with difficulty falls or slow for age	1	1	1	0	1		0	1		1	1	1	1	0	1	0	
	Moves within room with no difficulty	1	1	1	0	1		0	1		1	1	1	1	0	1	0	

	Moves between rooms but with difficulty falls or slow for age	1	1	1	0	1		0	1		1	1	1	1	0	1	0	
	Moves between rooms with no difficulty	0	1	1	0	1		0	1		0	1	1	1	0	1	0	
	Moves indoors 50 feet, opens and closes inside and outside doors	0	1	0	0	1		0	1		0	1	1	1	0	1	0	
Indoor locomotion pulls or carries objects	Changes physical location purposely	1	1	1	1	1		0	1		1	1	1	1	0	1	1	
	Moves objects along floor	1	1	1	1	1		0	1		1	1	1	1	0	1	0	
	Carries objects small enough to be held in one hand	1	1	1	0	1		0	1		1	1	1	1	0	1	0	
	Carries object large enough to require two hands	1	1	1	0	1		0	1		1	1	1	1	0	1	0	
	Carries fragile or spillable objects	1	1	0	0	1		0	1		0	1	0	1	0	1	0	
Outdoor locomotion	Walks but holds onto objects, caregiver or device for support	1	1	1	0	1		0	1		1	1	1	1	0	1	0	
	Walks without support	1	1	1	0	1		0	1		1	1	1	1	0	1	0	
Outdoor locomotion distance and speed	Moves 10 to 50 feet (1 to 5 car lengths)	1	1	1	0	1		0	1		1	1	1	1	0	1	0	
	Moves 50 to 100 feet (1 to 10 car lengths)	1	1	1	0	1		0	1		1	1	1	1	0	1	0	
	Moves 100 to 150 feet (35 to 50 yards)	1	1	1	0	1		0	1		1	1	1	1	0	1	0	
	Moves 150 feet and longer but with difficulty (stumbles slow for age	1	1	1	0	1		0	1		1	1	1	1	0	1	0	
	Moves 150 feet and longer with no difficulty	0	1	0	0	1		0	1		0	1	1	1	0	1	0	
Outdoor locomotion surfaces	Level surfaces (sidewalks, driveways		1	1	0	1		0	1		1	1	1	1	0	1	0	
	Slightly uneven surfaces (cracked pavement)	1	1	1	0	1		0	1		0	1	1	1	0	1	0	
	Rough, uneven surfaces (lawns, gravel)	1	1	1	0	1		0	1		0	1	1	1	0	1	0	
	Up and down an incline or ramps	1	1	0	0	1		0	1		0	1	1	1	0	1	0	
	Up and down curbs	1	1	0	0	1		0	1		0	1	1	1	0	1	0	
Upstairs	Scoots or crawls up partial flight 1 to 11 steps	1	1	1	0	1		0	1		1	1	1	1	0	1	0	
	Scoots and crawls up full flight (12 to 15 steps)	1	1	1	0	1		0	1		1	1	1	1	0	1	0	
	Walks up partial flight	1	1	1	0	1		0	1		1	1	1	1	0	1	0	
	Walks up full flight, but with difficulty (slow for age)	1	1	1	0	1		0	1		0	1	1	1	0	1	0	
	Walks up entire flight with no difficulty	0	1	0	0	1		0	1		1	1	1	1	0	1	0	
Downstairs	Scoots or crawls down partial flight (1to 11	1	1	1	0	1		0	1		1	1	1	1	0	1	0	

	steps)																	
	Scoots or crawls down full flight of stairs (12 to 15 steps	1	1	1	0	1		0	1		1	1	1	1	0	1	0	
	Walks down partial flight	1	1	0	0	1		0	1		1	1	1	1	0	1	0	
	Walks down full flight, but with difficulty (slow for age)	1	1	0	0	1		0	1		1	1	1	1	0	1	0	
	Walks down full flight with no difficulty	0	1	0	0	0		0	1		0	1	0	1	0	1	0	
Week 9 Toilet transfers	Sits if supported by equipment or caregiver3	1	1	1	1	1	1	1	1		1	1	1	1	1	1	1	
	Sits unsupported on toilet or potty chair	1	1	1	0	1	1	0	1		1	1	1	1	0	1	0	
	Gets on and off low toilet or potty	1	1	1	0	1	1	0	1		1	1	1	1	0	1	0	
	Gets on and off adult size toilet	1	1	1	0	1	1	0	1		1	1	0	1	0	1	0	
	Gets on and off toilet not needing own arms	1	1	0	0	1	1	0	1		1	1	0	1	0	1	0	
Chair or wheelchair transfers	Sits if supported by equipment or caregiver	1	1	1	1	1	1	1	1		1	1	1	1	1	1	1	
	Sits unsupported on chair or bench	1	1	1	0	1	1	1	1		1	1	1	1	0	1	0	
	Gets on and off low chair or furniture	1	1	1	0	1	1	1	1		1	1	1	1	0	1	0	
	Gets on and off adult size chair or wheelchair	1	1	1	0	1	1	1	1		1	1	1	1	0	1	0	
	Gets in and out of chair, not needing arms	1	1	0	0	1	1	0	1		1	1	0	1	0	1	0	
Car transfers	Moves in car, scoots on seat or gets in and out of car seat	1	1	1	0	1	1	0	1		1	1	1	1	0	1	0	
	Gets in and out of car with little assistance or instruction	1	1	1	0	1	1	0	1		1	1	1	1	0	1	0	
	Gets in and out of car with no assistance or instruction	1	1	0	0	1	1	0	1		0	1	1	1	0	1	0	
	Manages seatbelt or chair restraint	1	1	0	0	1	0	0	1		0	1	0	1	0	1	0	
	Gets in and out of car and opens and closes car door	0	1	0	0	1	0	0	1		0	1	0	1	0	1	0	
Bed mobility or transfers	Raises to sitting position in bed or crib	1	1	1	0	1	1	1	1		1	1	1	1	0	1	0	
	Comes to sit on edge of bed, lies down from sitting at edge of bed	1	1	1	0	1	1	1	1		1	1	1	1	0	1	0	
	Gets in and out of own bed,	1	1	0	0	1	1	1	1		0	1	1	1	0	1	0	
	Gets in and out of own bed, not needing own arms	1	1	0	0	1	1	0	1		1	1	1	1	0	1	0	
Tub transfers	Sits if supported by equipment or caregiver in a tub or sink	1	1	1	1	1	1	0	1		1	1	1	1	0	1	1	
	Sits unsupported and moves in tub	1	1	1	0	1	1	0	1		1	1	1	1	0	1	0	
	Climbs and scoots in and	1	1	0	0	1	0	0	1		1	1	1	1	0	1	0	

	out of tub																	
	Sits down and stand up from inside tub	0	1	0	0	1	0	0	1		1	1	1	1	0	1	0	
	Steps or transfers into and out of adult sized tub	0	1	0	0	1	0	0	1		0	1	0	1	0	1	0	
Indoor locomotion methods	Rolls, scoots, crawls or creeps on floor	1	1	1	1	1	1	1	1		1	1	1	1	1	1	1	
	Walks, but holds onto furniture, walls, caregivers or uses a device for support	1	1	1	0	1	1	0	1		1	1	1	1	0	1	0	
	Walks without support	1	1	1	0	1	1	0	1		1	1	1	1	0	1	0	
Indoor locomotion distance or speed	Moves within a room but with difficulty falls or slow for age	1	1	1	0	1	1	0	1		1	1	1	1	0	1	0	
	Moves within room with no difficulty	1	1	1	0	1	1	0	1		1	1	1	1	0	1	0	
	Moves between rooms but with difficulty falls or slow for age	1	1	1	0	1	1	0	1		1	1	1	1	0	1	0	
	Moves between rooms with no difficulty	1	1	1	0	1	1	0	1		0	1	1	1	0	1	0	
	Moves indoors 50 feet, opens and closes inside and outside doors	1	1	0	0	1	0	0	1		0	1	1	1	0	1	0	
Indoor locomotion pulls or carries objects	Changes physical location purposely	1	1	1	1	1	1	0	1		1	1	1	1	0	1	1	
	Moves objects along floor	1	1	1	1	1	1	0	1		1	1	1	1	0	1	0	
	Carries objects small enough to be held in one hand	1	1	1	0	1	1	0	1		1	1	1	1	0	1	0	
	Carries object large enough to require two hands	1	1	1	0	1	1	0	1		0	1	1	1	0	1	0	
	Carries fragile or spill able objects	0	1	0	0	1	0	0	1		1	1	0	0	0	1	0	
Outdoor locomotion	Walks but holds onto objects, caregiver or device for support	1	1	1	0	1	1	0	1		1	1	1	1	0	1	0	
	Walks without support	1	1	1	0	1	1	0	1		1	1	1	1	0	1	0	
Outdoor locomotion distance and speed	Moves 10 to 50 feet (1 to 5 car lengths)	1	1	1	0	1	1	0	1		1	1	1	1	0	1	0	
	Moves 50 to 100 feet (1 to 10 car lengths)	1	1	1	0	1	1	0	1		1	1	1	1	0	1	0	
	Moves 100 to 150 feet (35 to 50 yards)	1	1	1	0	1	1	0	1		1	1	1	1	0	1	0	
	Moves 150 feet and longer but with difficulty (stumbles slow for age	1	1	1	0	1	1	0	1		1	1	1	1	0	1	0	
	Moves 150 feet and longer with no difficulty	0	1	0	0	1	1	0	1		0	0	1	1	0	1	0	
Outdoor locomotion surfaces	Level surfaces (sidewalks, driveways	1	1	1	0	1	1	0	1		1	1	1	1	0	1	0	

	Slightly uneven surfaces (cracked pavement)	1	1	1	0	1	1	0	1		0	1	1	1	0	1	0	
	Rough, uneven surfaces (lawns, gravel)	1	1	1	0	1	1	0	1		0	1	1	1	0	1	0	
	Up and down an incline or ramps	1	1	1	0	1	1	0	1		0	1	1	1	0	1	0	
	Up and down curbs	1	1	0	0	1	1	0	1		0	1	1	1	0	1	0	
Upstairs	Scoots or crawls up partial flight 1 to 11 steps	1	1	1	0	1	1	0	1		1	1	1	1	0	1	0	
	Scoots and crawls up full flight (12 to 15 steps)	1	1	1	0	1	1	0	1		1	1	1	1	0	1	0	
	Walks up partial flight	1	1	1	0	1	1	0	1		1	1	1	1	0	1	0	
	Walks up full flight, but with difficulty (slow for age)	1	1	0	0	1	0	0	1		1	1	1	1	0	1	0	
	Walks up entire flight with no difficulty	0	1	0	0	1	0	0	1		1	1	1	1	0	1	0	
Downstairs	Scoots or crawls down partial flight (1to 11 steps)	1	1	1	0	1	1	0	1		0	1	1	1	0	1	0	
	Scoots or crawls down full flight of stairs (12 to 15 steps	1	1	1	0	1	1	0	1		1	1	1	1	0	1	0	
	Walks down partial flight	1	1	1	0	1	1	0	1		1	1	1	1	0	1	0	
	Walks down full flight, but with difficulty (slow for age)	1	1	0	0	1	0	0	1		1	1	1	1	0	1	0	
	Walks down full flight with no difficulty	0	1	0	0	1	0	0	1		0	1	1	1	0	1	0	
Week 13 Toilet transfers	Sits if supported by equipment or caregiver 4				1		1				0	1	1		1	1	1	
	Sits unsupported on toilet or potty chair				0		1				1	1	1		0	1	0	
	Gets on and off low toilet or potty				0		1				1	1	1		0	1	0	
	Gets on and off adult size toilet				0		1				1	1	1		0	1	0	
	Gets on and off toilet not needing own arms				0		1				1	1	1		0	1	0	
Chair or wheelchair transfers	Sits if supported by equipment or caregiver				1		1				1	1	1		1	1	1	
	Sits unsupported on chair or bench				0		1				1	1	1		0	1	0	
	Gets on and off low chair or furniture				0		1				1	1	1		0	1	0	
	Gets on and off adult size chair or wheelchair				0		0				1	1	1		0	1	0	
	Gets in and out of chair, not needing arms				0		1				1	1	1		0	1	0	
Car transfers	Moves in car, scoots on seat or gets in and out of car seat				0		1				1	1	1		0	1	0	
	Gets in and out of car with little assistance or instruction				0		1				1	1	1		0	1	0	
	Gets in and out of car with no assistance or instruction				0		1				1	1	1		0	1	0	
	Manages seatbelt or				0		0				0	1	0		0	1	0	

	chair restraint																	
	Gets in and out of car and opens and closes car door				0		0				0	1	0		0	1	0	
Bed mobility or transfers	Raises to sitting position in bed or crib				0		1				0	1	1		0	1	0	
	Comes to sit on edge of bed, lies down from sitting at edge of bed				0		1				1	1	1		0	1	0	
	Gets in and out of own bed,				0		0				1	1	1		0	1	0	
	Gets in and out of own bed, not needing own arms				0		0				0	1	0		0	1	0	
Tub transfers	Sits if supported by equipment or caregiver in a tub or sink				1		1				1	1	1		0	1	1	
	Sits unsupported and moves in tub				0		1				1	1	1		0	1	0	
	Climbs and scoots in and out of tub				0		0				1	1	1		0	1	0	
	Sits down and stand up from inside tub				0		0				1	1	1		0	1	0	
	Steps or transfers into and out of adult sized tub				0		0				1	1	1		0	1	0	
Indoor locomotion methods	Rolls, scoots, crawls or creeps on floor				1		1				0	1	1		1	1	1	
	Walks, but holds onto furniture, walls, caregivers or uses a device for support				0		1				1	1	1		0	1	0	
	Walks without support				0		1				1	1	1		0	1	0	
Indoor locomotion distance or speed	Moves within a room but with difficulty falls or slow for age				0		1				1	1	1		0	1	0	
	Moves within room with no difficulty				0		1				1	1	1		0	1	0	
	Moves between rooms but with difficulty falls or slow for age				0		1				1	1	1		0	1	0	
	Moves between rooms with no difficulty				0		1				1	1	1		0	1	0	
	Moves indoors 50 feet, opens and closes inside and outside doors				0		1				0	1	1		0	1	0	
Indoor locomotion pulls or carries objects	Changes physical location purposely				1		1				0	1	1		0	1	1	
	Moves objects along floor				1		1				1	1	1		0	1	0	
	Carries objects small enough to be held in one hand				0		1				1	1	1		0	1	0	
	Carries object large enough to require two hands				0		0				1	1	1		0	1	0	
	Carries fragile or spill able objects				0		0				0	0	1		0	1	0	

Outdoor locomotion	Walks but holds onto objects, caregiver or device for support				0		1				1	1	1		0	1	0	
	Walks without support				0		0				1	1	1		0	1	0	
Outdoor locomotion distance and speed	Moves 10 to 50 feet (1 to 5 car lengths)				0		0				1	1	1		0	1	0	
	Moves 50 to 100 feet (1 to 10 car lengths)				0		0				1	1	1		0	1	0	
	Moves 100 to 150 feet (35 to 50 yards)				0		0				1	1	1		0	1	0	
	Moves 150 feet and longer but with difficulty (stumbles slow for age				0		0				1	1	1		0	1	0	
	Moves 150 feet and longer with no difficulty				0		1				1	1	1		0	1	0	
Outdoor locomotion surfaces	Level surfaces sidewalks, driveways				0		1				0	1	1		0	1	0	
	Slightly uneven surfaces (cracked pavement)				0		1				1	1	1		0	1	0	
	Rough, uneven surfaces (lawns, gravel)				0		1				0	1	1		0	1	0	
	Up and down an incline or ramps				0		1				0	1	1		0	1	0	
	Up and down curbs				0		1				0	1	1		0	1	0	
Upstairs	Scoots or crawls up partial flight 1 to 11 steps				0		1				0	1	1		0	1	0	
	Scoots and crawls up full flight (12 to 15 steps)				0		1				1	1	1		0	1	0	
	Walks up partial flight				0		1				1	1	1		0	1	0	
	Walks up full flight, but with difficulty (slow for age)				0		0				1	1	1		0	1	0	
	Walks up entire flight with no difficulty				0		0				1	1	1		0	1	0	
Downstairs	Scoots or crawls down partial flight (1to 11 steps)				0		1				1	1	1		0	1	0	
	Scoots or crawls down full flight of stairs (12 to 15 steps				0		1				0	1	1		0	1	0	
	Walks down partial flight				0		1				1	1	1		0	1	0	
	Walks down full flight, but with difficulty (slow for age)				0		0				1	1	1		0	1	0	
	Walks down full flight with no difficulty				0		0				1	1	1		0	1	0	

6.4.2 Self-care

Self-care domain	Child id number	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17
Baseline	Eats pureed /blended /strained foods	1	1	1	1	1	1	0	1	1	1	1	1	1	1	1	1	1
	Eats ground/ lumpy food	1	1	1	1	1	1	0	1	1	1	1	1	1	1	1	1	1
	Eats cut up/chunky/diced food	1	1	1	1	1	1	0	1	1	1	1	1	1	1	1	0	1
	Eats all textures of table food	1	1	1	1	1	1	0	1	1	1	1	1	1	1	1	0	1
Use of utensils	Finger feeds	1	1	0	0	1	1	0	1	1	1	1	1	1	0	1	0	1
	Scoops with a spoon and brings to mouth	1	1	0	0	1	1	0	1	1	1	1	1	1	0	1	0	1
	Uses a spoon well	1	1	0	0	1	0	0	1	1	0	1	1	1	0	1	0	1
	Uses a fork well	0	1	0	0	1	0	0	1	1	0	0	0	0	0	1	0	1
	Uses a knife to butter, cut soft foods	0	0	0	0	1	0	0	1	1	0	0	0	0	0	0	0	1
Use of drinking containers	Hold bottle/ spout cup	1	1	0	0	1	1	0	1	1	1	1	1	1	0	1	0	1
	Lift cup to drink, but cup may tip	1	1	0	0	1	1	0	1	1	1	1	1	1	0	1	0	1
	Lifts open cup securely with two hands	1	1	0	0	1	1	0	1	1	0	1	1	1	0	1	0	1
	Lifts cup securely with one hand	1	1	0	0	1	0	0	1	1	0	1	1	1	0	1	0	1
	Pours liquid from a carton or pitcher	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1
Tooth brushing	Opens mouth for teeth to be brushed	1	1	0	0	1	0	1	1	1	1	1	1	1	0	1	1	1
	Holds toothbrush	1	1	0	0	1	0	0	1	1	1	1	1	1	0	1	0	1
	Brushes teeth but not a thorough job	1	1	0	0	1	1	0	1	1	1	1	0	1	0	1	0	1
	Thoroughly brushes teeth	1	1	0	0	1	1	0	1	1	0	1	0	1	0	1	0	1
	Prepares toothbrush with a tooth paste	0	1	0	0	1	1	0	0	0	1	0	0	0	0	0	0	1
Hair brushing	Hold head in position while hair is combed	1	1	0	0	1	1	1	1	1	1	1	1	1	0	1	0	1
	Brings brush or comb to hair	1	1	0	0	1	1	1	1	1	1	1	1	1	0	1	0	1
	Brushes or combs hair	1	1	0	0	1	0	0	0	1	0	0	1	1	0	1	0	1
	Manages tangles and parts hair	0	1	0	0	1	0	0	0	1	0	0	0	0	0	1	0	1
Nose care	Allows nose to be wiped	1	1	0	1	1	1	1	1	1	1	1	1	1	0	1	1	1
	Blows nose into held tissue	1	1	0	0	1	1	1	1	1	1	1	1	1	0	1	0	1
	Wipes nose using tissue on request	1	1	0	0	1	0	1	1	1	1	1	1	1	0	1	0	1
	Wipes nose using tissue without request	1	1	0	0	1	0	1	1	1	0	1	1	0	0	1	0	1
	Blows and wipes nose	0	1	0	0	1	0	1	1	0	0	1	0	0	0	1	0	1

	without request																	
Handwashing	Holds hands out to be washed	1	1	0	0	1	1	1	1	1	1	1	1	1	0	1	0	1
	Rubs hands together to be cleaned	1	1	0	0	1	1	1	1	1	0	1	1	1	0	1	0	1
	Turns water on and off, obtains soap	1	1	0	0	1	0	0	1	1	0	0	1	1	0	1	0	1
	Washes hands thoroughly	1	1	0	0	1	0	0	1	1	0	0	1	1	0	1	0	1
	Dries hands thoroughly	1	1	0	0	1	0	0	1	1	1	0	1	1	0	1	0	1
Washing body and face	Tries to wash parts of body	1	1	0	0	1	0	1	1	1	0	1	1	1	0	1	0	1
	Washes body thoroughly, not including face	0	1	0	0	1	0	0	1	1	0	0	0	1	0	1	0	1
	Obtains soap (and soaps washcloth if used)	1	1	0	0	1	0	0	1	1	0	1	1	1	0	1	0	1
	Dries body thoroughly	0	1	0	0	1	0	0	0	1	0	0	0	0	0	1	0	1
	Washes and dries face thoroughly	0	1	0	0	0	0	0	0	1	0	0	0	0	0	1	0	1
Pullover/ front opening garments	Assist, such as pushing arms through shirt	1	1	0	1	1	1	1	1	1	1	1	1	1	0	1	0	1
	Removes T-shirt, dress or sweater no fasteners	0	1	0	0	1	0	0	1	1	0	1	1	1	0	1	0	1
	Puts on T-shirt, dress or sweater	0	1	0	0	1	0	0	1	1	0	0	1	1	0	1	0	0
	Puts on and removes front opening shirt not including fasteners	0	1	0	0	0	0	0	1	1	0	1	0	0	0	1	0	0
	Puts on and removes front opening shirt, including fasteners	0	1	0	0	0	0	0	1	1	0	0	0	0	0	0	0	0
Fasteners	Tries to assist with fasteners	1	1	0	0	0	0	0	1	1	0	1	1	0	0	0	0	0
	Zips and unzips, doesn't separate or hook zipper	1	1	0	0	0	0	0	1	1	0	1	1	0	0	0	0	0
	Snaps and unsnaps	0	1	0	0	0	0	0	1	1	0	1	0	0	0	1	0	0
	Buttons and unbuttons	0	1	0	0	0	0	0	0	1	0	0	0	0	0	0	0	0
	Zips and unzips, separates and hooks, zipper	0	1	0	0	0	0	0	1	1	0	0	0	0	0	0	0	0
Pants	Assists, such as pushing legs through pants, Removes pants with elastic waist	1	1	0	0	1	0	1	1	1	1	1	1	1	0	1	0	1
	Removes pants with elastic waist	0	1	0	0	1	0	0	1	1	0	0	1	1	0	1	0	1
	Puts on pants with elastic waist	0	1	0	0	1	0	0	1	1	0	0	0	1	0	1	0	0
	Removes pants, including unfastening,	0	1	0	0	1	0	0	1	1	0	0	0	0	0	0	0	0
	Puts on pants, including fastening	0	1	0	0	1	0	0	1	1	0	0	0	0	0	0	0	0
Shoes/socks	Removes socks and unfastened shoes	1	1	0	0	1	1	0	1	1	0	1	1	1	0	1	0	1
	Puts on unfastened shoes	1	1	0	0	1	1	0	1	1	0	0	1	1	0	1	0	1
	Puts on socks	0	1	0	0	1	0	0	1	1	0	0	0	1	0	1	0	1

	Puts on shoes on correct feet, manages Velcro fasteners	0	1	0	0	1	0	0	1	1	0	0	0	0	0	1	0	1
	Ties shoelaces	0	1	0	0	0	0	0	1	1	0	0	0	0	0	0	0	0
Toileting tasks	Assists with clothing management	1	1	0	0	1	0	0	1	1	0	1	1	1	0	1	0	1
	Tries to wipe self after toileting	1	1	0	0	1	0	0	1	1	0	0	0	1	0	1	0	1
	Manages toilet seat, gets toilet paper and flushes toilet	1	1	0	0	1	0	0	1	1	0	0	0	1	0	1	0	1
	Manages clothes before and after toileting	1	1	0	0	1	0	0	1	1	0	0	0	1	0	1	0	1
	Wipes self thoroughly after bowel movements	1	1	0	0	1	0	0	0	1	0	0	0	0	0	1	0	1
Management of bladder	Indicates when wet in diapers or training pants	1	1	0	0	1	1	1	1	1	1	1	1	1	0	1	0	1
	Occasionally indicates need to urinate (daytime)	1	1	0	0	1	0	0	1	1	0	1	1	1	0	1	0	1
	Consistently indicates need to urinate with time to get to toilet (daytime)	1	1	0	0	1	0	0	0	1	0	1	1	1	0	1	0	1
	Takes self to toilet to urinate (daytime)	1	1	0	0	1	0	0	0	1	0	0	1	0	0	1	0	1
	Consistently stays dry day and night	1	1	0	0	1	0	0	0	1	0	0	1	1	0	1	0	1
Management of bowel	Indicates need to be changed	1	1	0	1	1	1	1	1	1	1	1	1	1	0	1	0	1
	Occasionally indicates need to use toilet(daytime)	1	1	0	0	1	0	0	1	1	0	1	1	1	0	1	0	1
	Consistently indicates need to use toilet with time to get to toilet (day time)	1	1	0	0	1	0	0	1	1	0	1	1	1	0	1	0	1
	Distinguishes between need for urination and bowel movements	1	1	0	0	1	0	0	1	1	0	1	1	1	0	1	0	1
	Takes self to bathroom for bowel movements, has no bowel accidents	1	1	0	0	1	0	0	1	1	0	0	1	1	0	1	0	1
Week 3 Food textures	Eats pureed /blended /strained foods	1	1	1	1	1	1		1	1	1	1	1	1	0	1	1	1
	Eats ground/ lumpy food	1	1	1	1	1	1		1	1	1	1	1		1	1	1	1
	Eats cut up/chunky/diced food	1	1	1	1	1	1		1	1	1	1	1		1	1	0	1
	Eats all textures of table food	1	1	1	1	1	1		1	1	1	1	1		1	1	0	1
Use of utensils	Finger feeds	1	1	1	0	1	1		1	1	1	1	1		0	1	0	1
	Scoops with a spoon and brings to mouth	1	1	1	0	1	1		1	1	1	1	1		0	1	0	1
	Uses a spoon well	1	1	0	0	1	1		1	1	1	1	1		0	1	0	1
	Uses a fork well	1	1	0	0	0	1		1	1	1	1	1		0	1	0	1
	Uses a knife to butter, cut soft foods	0	0	0	0	0	0		0	0	0	0	1		0	0	0	1
Use of drinking	Hold bottle/ spout cup	1	1	1	0	1	1		1	1	1	1	1		0	1	0	1

containers																			
	Lift cup to drink, but cup may tip	1	1	1	0	1	1		1	1	1	1	1		0	1	0	1
	Lifts open cup securely with two hands	1	1	1	0	1	1		1	1	1	1	1		0	1	0	1
	Lifts cup securely with one hand	1	1	1	0	1	0		1	1	1	1	1		0	1	0	1
	Pours liquid from a carton or pitcher	0	1	0	0	1	0		1	1	0	0	1		0	0	0	1
Tooth brushing	Opens mouth for teeth to be brushed	1	1	1	1	1	1		1	1	1	1	1		0	1	1	1
	Holds toothbrush	1	1	0	0	1	1		1	1	1	1	1		0	1	0	1
	Brushes teeth but not a thorough job	1	1	0	0	1	0		1	1	1	1	1		0	1	0	1
	Thoroughly brushes teeth	1	1	0	0	1	0		1	1	0	1	1		0	1	0	1
	Prepares toothbrush with a tooth paste	0	1	0	0	1	0		1	1	0	0	1		0	1	0	1
Hair brushing	Hold head in position while hair is combed	1	1	1	1	1	1		1	1	1	1	1		0	1	1	1
	Brings brush or comb to hair	1	1	0	0	1	1		1	1	1	1	1		0	1	0	1
	Brushes or combs hair	1	1	0	0	0	0		1	1	0	1	1		0	1	0	1
	Manages tangles and parts hair	0	1	0	0	0	0		0	1	0	0	1		0	1	0	1
Nose care	Allows nose to be wiped	1	1	1	1	1	1		1	1	1	1	1		0	1	1	1
	Blows nose into held tissue	1	1	1	0	1	1		1	1	1	1	1		0	1	0	1
	Wipes nose using tissue on request	1	1	1	0	1	0		1	1	1	1	1		0	1	0	1
	Wipes nose using tissue without request	1	1	1	0	1	1		1	1	1	0	1		0	1	0	1
	Blows and wipes without request	0	1	0	0	1	0		1	1	1	0	1		0	1	0	1
Handwashing	Holds hands out to be washed	1	1	1	1	1	1		1	1	1	1	1		0	1	0	1
	Rubs hands together to be cleaned	1	1	1	0	1	0		1	1	1	1	1		0	1	0	1
	Turns water on and off, obtains soap	1	1	0	0	1	0		1	1	1	1	1		0	1	0	1
	Washes hands thoroughly	1	1	0	0	1	0		1	1	1	1	1		0	1	0	1
	Dries hands thoroughly	1	1	0	0	1	0		1	1	1	1	1		0	1	0	1
Washing body and face	Tries to wash parts of body	1	1		0	1	1		1	1	1	1	1		0	1	0	1
	Washes body thoroughly, not including face	0	1	1	0	1	0		1	1	0	1	1		0	1	0	1
	Obtains soap (and soaps washcloth if used)	0	1	0	0	1	0		1	1	0	1	1		0	1	0	1
	Dries body thoroughly	0	1	0	0	1	0		1	1	0	0	1		0	1	0	1
	Washes and dries face thoroughly	0	1	0	0	1	0		1	1	0	0	1		0	1	0	1
Pullover/ front opening garments	Assist, such as pushing arms through shirt	1	1	1	0	1	0		1	1	1	1	1		0	1	0	1
	Removes T-shirt, dress or sweater no fasteners	0	1	0	0	1	0		1	1	1	1	1		0	1	0	1

	Puts on T-shirt, dress or sweater	0	1	0	0	1	0		1	1	0	1	1		0	1	0	1
	Puts on and removes front opening shirt not including fasteners	0	1	0	0	1	0		1	1	0	0	1		0	0	0	1
	Puts on and removes front opening shirt, including fasteners	0	1	0	0	1	0		1	1	0	0	1		0	0	0	1
Fasteners	Tries to assist with fasteners	0	1	0	0	0	0		1	1	0	0	1		0	1	0	1
	Zips and unzips, doesn't separate or hook zipper	0	1	0	0	0	0		1	1	0	1	1		0	0	0	1
	Snaps and unsnaps	0	1	0	0	0	0		1	1	0	0	1		0	1	0	1
	Buttons and unbuttons	0	1	0	0	0	0		1	1	0	0	1		0	0	0	1
	Zips and unzips, separates and hooks, zipper	0	1	0	0	0	0		1	1	0	0	1		0	0	0	0
Pants	Assists, such as pushing legs through pants, Removes pants with elastic waist	1	1	1	0	1	1		1	1	1	0	1		0	1	0	1
	Removes pants with elastic waist	1	1	0	0	1	0		1	1	1	1	1		0	1	0	1
	Puts on pants with elastic band	1	1	0	0	1	0		1	1	0	1	1		0	1	0	1
	Removes pants, including unfastening,	0	1	0	0	1	0		1	1	0	1	1		0	0	0	1
	Puts on pants, including fastening	0	1	0	0	1	0		1	1	0	0	1		0	0	0	1
Shoes/socks	Removes socks and unfastened shoes	1	1	0	0	1	0		1	1	1	1	1		0	1	0	1
	Puts on unfastened shoes	1	1	1	0	1	0		1	1	1	1	1		0	1	0	1
	Puts on socks	1	1	0	0	1	0		1	1	1	1	1		0	1	0	1
	Puts on shoes on correct feet, manages Velcro fasteners	0	1	0	0	1	0		1	1	0	1	1		0	1	0	1
	Ties shoelaces	0	1	0	0	1	0		1	1	0	0	1		0	0	0	1
Toileting tasks	Assists with clothing management	1	1	0	0	1	1		1	1	1	1	1		0	1	0	1
	Tries to wipe self after toileting	1	1	0	0	1	1		1	1	1	1	1		0	1	0	1
	Manages toilet seat, gets toilet paper and flushes toilet	1	1	0	0	1	0		1	1	1	1	1		0	1	0	1
	Manages clothes before and after toileting	1	1	0	0	1	0		1	1	1	1	1		0	1	0	1
	Wipes self thoroughly after bowel movements	1	1	0	0	1	0		1	1	1	1	1		0	1	0	1
Management of bladder	Indicates when wet in diapers or training pants	1	1	0	1	1	1		1	1	1	1	1		0	1	1	1
	Occasionally indicates need to urinate (daytime)	1	1	0	0	1	1		1	1	1	1	1		0	1	0	1
	Consistently indicates need to urinate with time to get to toilet (daytime)	1	1	0	0	1	0		1	1	1	1	1		0	1	0	1
	Takes self to toilet to urinate (daytime)	1	1	0	0	1	0		1	1	1	1	1		0	1	0	1

	Consistently stays dry day and night	1	1	0	0	1	0		1	1	1	1	1		0	1	0	1
Management of bowel	Indicates need to be changed	1	1	0	1	1	1		1	1	1	1	1		0	1	1	1
	Occasionally indicates need to use toilet(daytime)	1	1	0	0	1	1		1	1	1	1	1		0	1	0	1
	Consistently indicates need to use toilet with time to get to toilet (day time)	1	1	0	0	1	1		1	1	1	1	1		0	1	0	1
	Distinguishes between need for urination and bowel movements	1	1	0	0	1	1		1	1	1	1	1		0	1	0	1
	Takes self to bathroom for bowel movements, has no bowel accidents	1	1	0	0	1	0		1	1	1	1	1		0	1	0	1
Week 7 Food textures	Eats pureed /blended /strained foods	1	1	1	1	1		0	1		1	1	1	1	1	1	1	
	Eats ground/ lumpy food	1	1	1	1	1		0	1		1	1	1	1	1	1	1	
	Eats cut up/chunky/diced food	1	1	1	1	1		0	1		1	1	1	1	1	1	0	
	Eats all textures of table food	1	1	1	1	1		0	1		1	1	1	1	1	1	0	
Use of utensils	Finger feeds	1	1	1	1	1		0	1		1	1	1	1	1	1	1	
	Scoops with a spoon and brings to mouth	1	1	1	0	1		0	1		1	1	1	1	0	1	1	
	Uses a spoon well	1	1	1	0	1		0	1		1	1	1	1	0	1	0	
	Uses a fork well	1	1	0	0	1		0	1		1	1	1	0	0	0	0	
	Uses a knife to butter, cut soft foods	0	1	0	0	1		0	1		0	0	0	1	0	0	0	
Use of drinking containers	Hold bottle/ spout cup	1	1	1	1	1		0	1		1	1	1	1	1	1	0	
	Lift cup to drink, but cup may tip	1	1	1	1	1		0	1		1	1	1	1	0	1	0	
	Lifts open cup securely with two hands	1	1	1	1	1		0	1		1	1	1	1	0	1	0	
	Lifts cup securely with one hand	1	1	1	0	1		0	1		1	1	1	1	0	1	0	
	Pours liquid from a carton or pitcher	0	1	0	0	1		0	1		0	0	0	1	0	0	0	
Tooth brushing	Opens mouth for teeth to be brushed	1	1	1	1	1		1	1		1	1	1	1	1	1	1	
	Holds toothbrush	1	1	1	1	1		1	1		1	1	1	1	0	1	0	
	Brushes teeth but not a thorough job	1	1	1	1	1		1	1		1	1	1	1	0	1	0	
	Thoroughly brushes teeth	1	1	0	0	1		0	1		1	1	1	1	0	1	0	
	Prepares toothbrush with a tooth paste	1	1	0	0	1		0	1		0	1	0	1	0	1	0	
Hair brushing	Hold head in position while hair is combed	1	1	1	1	1		1	1		1	1	1	1	1	1	1	
	Brings brush or comb to hair	1	1	1	0	1		1	1		1	1	1	1	0	1	0	
	Brushes or combs hair	1	1	0	0	1		0	1		1	1	0	1	0	1	0	
	Manages tangles and	1	0	0	0	1		0	0		1	0	0	1	0	1	0	

	parts hair																	
Nose care	Allows nose to be wiped	1	1	1	1	1		1	1		1	1	1	1	1	1	1	
	Blows nose into held tissue	1	1	1	0	1		1	1		1	1	1	1	0	1	1	
	Wipes nose using tissue on request	1	1	1	0	1		1	1		1	1	1	1	0	1	0	
	Wipes nose using tissue without request	1	1	1	0	1		1	1		1	1	1	1	0	1	0	
	Blows and wipes nose without request	1	1	0	0	1		1	1		1	1	1	1	0	1	0	
Handwashing	Holds hands out to be washed	1	1	1	0	1		1	1		1	1	1	1	1	1	0	
	Rubs hands together to be cleaned	1	1	1	0	1		1	1		1	1	1	1	0	1	0	
	Turns water on and off, obtains soap	1	1	0	0	1		1	1		1	1	1	1	0	1	0	
	Washes hands thoroughly	1	1	1	0	1		0	1		1	1	1	1	0	1	0	
	Dries hands thoroughly	1	1	1	0	1		0	1		1	1	1	1	0	1	0	
Washing body and face	Tries to wash parts of body	1	1	1	0	1		1	1		1	1	1	1	0	1	0	
	Washes body thoroughly, not including face	1	1	0	0	1		0	1		1	0	0	1	0	1	0	
	Obtains soap (and soaps washcloth if used)	1	1	0	0	1		0	1		1	0	1	1	0	1	0	
	Dries body thoroughly	1	1	0	0	1		0	1		0	0	0	0	0	1	0	
	Washes and dries face thoroughly	1	1	0	0	1		0	1		0	0	1	0	0	1	0	
Pullover/ front opening garments	Assist, such as pushing arms through shirt	1	1	0	1	1		1	1		1	1	1	1	0	1	1	
	Removes T-shirt, dress or sweater no fasteners	1	1	0	0	1		0	1		1	1	1	1	0	1	0	
	Puts on T-shirt, dress or sweater	1	1	0	0	1		0	1		1	0	1	1	0	1	0	
	Puts on and removes front opening shirt not including fasteners	0	1	0	0	1		0	1		0	0	0	1	0	1	0	
	Puts on and removes front opening shirt, including fasteners	0	1	0	0	1		0	1		0	0	0	1	0	1	0	
Fasteners	Tries to assist with fasteners	0	1	0	0	1		0	1		0	1	1	1	0	1	0	
	Zips and unzips, doesn't separate or hook zipper	0	1	0	0	1		0	1		0	1	1	0	0	1	0	
	Snaps and unsnaps	0	1	0	0	1		0	1		0	0	0	1	0	1	0	
	Buttons and unbuttons	0	1	0	0	1		0	1		0	0	0	1	0	1	0	
	Zips and unzips, separates and hooks, zipper	0	1	0	0	1		0	1		0	0	0	0	0	1	0	
Pants	Assists, such as pushing legs through pants, Removes pants with elastic waist	1	1	1	1	1		0	1		1	1	1	1	0	1	1	
	Removes pants with elastic waist	1	1	0	0	1		0	1		1	1	1	1	0	1	0	
	Puts on pants with elastic	1	1	0	0	1		0	1		1	1	1	1	0	1	0	

	waist																	
	Removes pants, including unfastening,	0	1	0	0	1		0	1		0	0	0	1	0	1	0	
	Puts on pants, including fastening	0	1	0	0	1		0	1		0	0	0	1	0	1	0	
Shoes/socks	Removes socks and unfastened shoes	1	1	1	0	1		0	1		1	1	1	1	0	1	0	
	Puts on unfastened shoes	1	1	1	0	1		0	1		1	1	1	1	0	1	0	
	Puts on socks	1	1	0	0	1		0	1		1	1	0	1	0	1	0	
	Puts on shoes on correct feet, manages Velcro fasteners	0	1	0	0	1		0	1		1	1	0	1	0	1	0	
	Ties shoelaces	0	1	0	0	1		0	1		0	0	0	0	0	1	0	
Toileting tasks	Assists with clothing management	1	1	0	1	1		0	1		1	1	1	1	0	1	0	
	Tries to wipe self after toileting	1	1	0	0	1		0	1		1	1	0	1	0	1	0	
	Manages toilet seat, gets toilet paper and flushes toilet	1	1	0	0	1		0	1		1	1	0	1	0	1	0	
	Manages clothes before and after toileting	1	1	0	0	1		0	1		1	1	0	1	0	1	0	
	Wipes self thoroughly after bowel movements	1	1	0	0	1		0	1		1	1	0	1	0	1	1	
Management of bladder	Indicates when wet in diapers or training pants	1	1	0	1	1		1	1		1	1	1	1	0	1	1	
	Occasionally indicates need to urinate (daytime)	1	1	0	1	1		0	1		1	1	1	1	0	1	0	
	Consistently indicates need to urinate with time to get to toilet (daytime)	1	1	0	0	1		0	1		1	1	1	1	0	1	0	
	Takes self to toilet to urinate (daytime)	1	1	0	0	1		0	1		1	1	1	1	0	1	0	
	Consistently stays dry day and night	1	1	0	0	1		0	1		1	1	1	1	0	1	0	
Management of bowel	Indicates need to be changed	1	1	0	1	1		1	1		1	1	1	1	0	1	1	
	Occasionally indicates need to use toilet(daytime)	1	1	0	1	1		0	1		1	1	1	1	0	1	1	
	Consistently indicates need to use toilet with time to get to toilet (day time)	1	1	0	0	1		0	1		1	1	1	1	0	1	0	
	Distinguishes between need for urination and bowel movements	1	1	0	0	1		0	1		1	1	1	1	0	1	0	
	Takes self to bathroom for bowel movements, has no bowel accidents	1	1	0	0	1		0	1		1	1	1	1	0	1	0	
Week 9	Eats pureed /blended /strained foods	1		1	1	1	1	0	1			1	1	1	1	1	1	
	Eats ground/ lumpy food	1		1	1	1	1	0	1			1	1	1	1	1	1	
	Eats cut up/chunky/diced food	1		1	1	1	1	0	1			1	1	1	1	1	0	
	Eats all textures of table	1		1	1	1	1	0	1			1	1	1	1	1	0	

	food																	
Use of utensils	Finger feeds	1		1	1	1	1	0	1			1	1	1	1	1	1	
	Scoops with a spoon and brings to mouth	1		1	1	1	1	0	1			1	1	1	0	1	0	
	Uses a spoon well	1		0	0	1	1	0	1			1	1	1	0	1	0	
	Uses a fork well	1		0	0	1	1	0	1			1	1	1	0	1	0	
	Uses a knife to butter, cut soft foods	0		0	0	1	0	0	1			0	0	0	0	0	0	
Use of drinking containers	Hold bottle/ spout cup	1		1	1	1	1	0	1			1	1	1	1	1	1	
	Lift cup to drink, but cup may tip	1		1	1	1	1	0	1			1	1	1	0	1	1	
	Lifts open cup securely with two hands	1		1	0	1	1	0	1			1	1	1	0	1	0	
	Lifts cup securely with one hand	1		1	0	1	0	0	1			1	1	1	0	1	0	
	Pours liquid from a carton or pitcher	0		0	0	1	0	0	1			0	0	1	0	0	0	
Tooth brushing	Opens mouth for teeth to be brushed	1		1	1	1	1	1	1			1	1	1	1	1	1	
	Holds toothbrush	1		1	1	1	1	1	1			1	1	1	0	1	0	
	Brushes teeth but not a thorough job	1		0	1	1	0	1	1			1	1	1	0	1	0	
	Thoroughly brushes teeth	1		0	0	1	0	0	1			1	1	0	0	1	0	
	Prepares toothbrush with a tooth paste	0		0	0	1	0	0	1			1	1	0	0	1	0	
Hair brushing	Hold head in position while hair is combed	1		1	1	1	1	1	1			1	1	1	1	1	1	
	Brings brush or comb to hair	1		0	1	1	1	1	1			1	1	1	0	1	1	
	Brushes or combs hair	1		0	1	1	1	0	1			0	1	1	0	1	0	
	Manages tangles and parts hair	0		0	0	1	0	0	0			0	0	0	0	0	0	
Nose care	Allows nose to be wiped	1		1	1	1	1	1	1			1	1	1	1	1	1	
	Blows nose into held tissue	1		1	1	1	1	1	1			1	1	1	0	1	1	
	Wipes nose using tissue on request	1		0	1	1	1	1	1			1	1	1	0	1	0	
	Wipes nose using tissue without request	1		0	0	1	0	0	1			1	0	1	0	1	0	
	Wipes and blows nose without request	1		0	0	1	0	0	1			1	0	1	0	1	0	
Handwashing	Holds hands out to be washed	1		1	1	1	1	1	1			1	1	1	1	1	1	
	Rubs hands together to be cleaned	1		1	1	1	1	1	1			1	1	1	0	1	1	
	Turns water on and off, obtains soap	1		1	0	1	0	0	1			1	1	1	0	1	0	
	Washes hands thoroughly	1		1	0	1	1	0	1			0	1	1	0	1	0	
	Dries hands thoroughly	1		0	0	1	0	0	1			0	1	1	0	1	0	
Washing body and face	Tries to wash parts of body	1		1	1	1	1	0	1			1	1	1	0	1	0	
	Washes body thoroughly, not including face	0		1	0	1	0	0	1			0	0	1	0	1	0	
	Obtains soap (and soaps	1		1	0	1	0	0	1			0	1	1	0	1	0	

	washcloth if used)																	
	Dries body thoroughly	0		0	0	1	0	0	1			0	0	1	0	1	0	
	Washes and dries face thoroughly	0		0	0	1	0	0	1			0	0	1	0	1	0	
Pullover/ front opening garments	Assist, such as pushing arms through shirt	1		1	1	1	1	1	1			1	1	1	0	1	1	
	Removes T-shirt, dress or sweater no fasteners	1		1	0	1	0	0	1			1	1	1	0	1	0	
	Puts on T-shirt, dress or sweater	1		0	0	1	0	0	1			0	1	1	0	1	0	
	Puts on and removes front opening shirt not including fasteners	1		0	0	1	0	0	1			0	0	1	0	1	0	
	Puts on and removes front opening shirt, including fasteners	0		0	0	1	0	0	1			0	0	0	0	1	0	
Fasteners	Tries to assist with fasteners	1		0	0	1	0	0	1			1	1	1	0	1	0	
	Zips and unzips, doesn't separate or hook zipper	1		0	0	1	0	0	1			1	1	1	0	1	0	
	Snaps and unsnaps	1		0	0	1	0	0	1			0	0	1	0	1	0	
	Buttons and unbuttons	0		0	0	1	0	0	1			1	0	0	0	1	0	
	Zips and unzips, separates and hooks, zipper	0		0	0	1	0	0	1			1	0	0	0	0	0	
Pants	Assists, such as pushing legs through pants, Removes pants with elastic waist	1		1	1	1	1	1	1			1	1	1	0	1	1	
	Removes pants with elastic waist	1		0	0	1	1	1	1			1	1	1	0	1	0	
	Puts on pants with elastic waist	1		0	0	1	0	1	1			1	1	1	0	1	0	
	Removes pants, including unfastening,	1		0	0	1	0	0	1			1	0	1	0	1	0	
	Puts on pants, including fastening	1		0	0	1	0	0	1			1	0	1	0	1	0	
Shoes/socks	Removes socks and unfastened shoes	1		1	0	1	0	1	1			1	1	1	0	1	0	
	Puts on unfastened shoes	1		1	0	1	0	1	1			1	1	1	0	1	0	
	Puts on socks	1		0	0	1	0	1	1			1	1	1	0	1	0	
	Puts on shoes on correct feet, manages Velcro fasteners	1		0	0	1	0	0	1			1	1	1	0	1	0	
	Ties shoelaces	0		0	0	1	0	0	1			0	0	1	0	1	0	
Toileting tasks	Assists with clothing management	1		0	0	1	1	1	1			1	1	1	0	1	0	
	Tries to wipe self after toileting	1		0	0	1	1	1	1			1	0	1	0	1	0	
	Manages toilet seat, gets toilet paper and flushes toilet	1		0	0	1	0	1	1			1	0	1	0	1	0	
	Manages clothes before and after toileting	1		0	0	1	0	1	1			1	0	1	0	1	0	
	Wipes self thoroughly	1		0	0	1	0	1	1			1	0	1	0	1	0	

	after bowel movements																	
Management of bladder	Indicates when wet in diapers or training pants	1		0	1	1	1	1	1			1	1	1	0	1	1	
	Occasionally indicates need to urinate (daytime)	1		0	0	1	1	0	1			1	1	1	0	1	1	
	Consistently indicates need to urinate with time to get to toilet (daytime)	1		0	0	1	1	0	1			1	1	1	0	1	0	
	Takes self to toilet to urinate (daytime)	1		0	0	1	0	0	1			1	1	1	0	1	0	
	Consistently stays dry day and night	1		0	0	1	0	0	1			1	1	1	0	1	0	
Management of bowel	Indicates need to be changed	1		0	1	1	1	1	1			1	1	1	0	1	1	
	Occasionally indicates need to use toilet(daytime)	1		0	1	1	1	0	1			1	1	1	0	1	0	
	Consistently indicates need to use toilet with time to get to toilet (day time)	1		0	0	1	1	0	1			1	1	1	0	1	0	
	Distinguishes between need for urination and bowel movements	1		0	0	1	0	0	1			1	1	1	0	1	0	
	Takes self to bathroom for bowel movements, has no bowel accidents	1		0	0	1	0	0	1			1	1	1	0	1	0	
Week 13 Food textures	Eats pureed /blended /strained foods				1	1	1				1	1	1		1	1	1	
	Eats ground/ lumpy food				1	1	1				1	1	1		1	1	1	
	Eats cut up/chunky/diced food				1	1	1				1	1	1		1	1	1	
	Eats all textures of table food				1	1	1				1	1	1		1	1	1	
Use of utensils	Finger feeds				1	1	1				1	1	1		1	1	1	
	Scoops with a spoon and brings to mouth				1	1	1				1	1	1		0	1	1	
	Uses a spoon well				0	1	1				1	1	1		0	1	0	
	Uses a fork well				0	1	1				1	1	1		0	1	0	
	Uses a knife to butter, cut soft foods				0	1	0				0	0	0		0	1	0	
Use of drinking containers	Hold bottle/ spout cup				1	1	1				1	1	1		1	1	0	
	Lift cup to drink, but cup may tip				1	1	1				1	1	1		0	1	0	
	Lifts open cup securely with two hands				1	1	1				1	1	1		0	1	0	
	Lifts cup securely with one hand				0	1	1				1	1	1		0	1	0	
	Pours liquid from a carton or pitcher				0	1	0				1	1	1		0	1	0	
Tooth brushing	Opens mouth for teeth to be brushed				1	1	1				1	1	1		1	1	1	
	Holds toothbrush				1	1	1				1	1	1		0	1	1	
	Brushes teeth but not a				1	1	1				1	1	1		0	1	0	

	thorough job																	
	Thoroughly brushes teeth				0	1	0				1	1	1		0	1	0	
	Prepares toothbrush with a tooth paste				0	1	0				1	1	0		0	1	0	
Hair brushing	Hold head in position while hair is combed				1	1	1				1	1	1		1	1	1	
	Brings brush or comb to hair				1	1	1				1	1	1		0	1	0	
	Brushes or combs hair				0	1	0				1	1	1		0	1	0	
	Manages tangles and parts hair				0	1	0				1	0	1		0	1	0	
Nose care	Allows nose to be wiped				1	1	1				1	1	0		1	1	1	
	Blows nose into held tissue				1	1	1				1	1	1		0	1	1	
	Wipes nose using tissue on request				1	1	1				1	1	1		0	1	1	
	Wipes nose using tissue without request				0	1	1				1	1	1		0	1	0	
	Blows nose and wipes nose without request				0	1	0				1	1	1		0	1	0	
Handwashing	Holds hands out to be washed				1	1	1				1	1	1		1	1	1	
	Rubs hands together to be cleaned				1	1	1				1	1	1		0	1	0	
	Turns water on and off, obtains soap				1	1	1				1	1	1		0	1	0	
	Washes hands thoroughly				0	1	1				1	1	1		0	1	0	
	Dries hands thoroughly				0	1	1				1	1	1		0	1	0	
Washing body and face	Tries to wash parts of body				1	1	1				1	1	1		0	1	1	
	Washes body thoroughly, not including face				0	1	0				1	1	1		0	1	0	
	Obtains soap (and soaps washcloth if used)				0	1	0				1	1	1		0	1	0	
	Dries body thoroughly				0	1	0				1	0	1		0	1	0	
	Washes and dries face thoroughly				0	1	0				0	0	1		0	1	0	
Pullover/ front opening garments	Assist, such as pushing arms through shirt				1	1	1				1	1	1		0	1	1	
	Removes T-shirt, dress or sweater no fasteners				1	1	0				1	1	1		0	1	0	
	Puts on T-shirt, dress or sweater				1	1	0				1	1	0		0	1	0	
	Puts on and removes front opening shirt not including fasteners				0	1	0				1	1	1		0	1	0	
	Puts on and removes front opening shirt, including fasteners				0	1	0				1	1	1		0	1	0	
Fasteners	Tries to assist with fasteners				0	1	1				1	1	1		0	1	1	
	Zips and unzips, doesn't separate or hook zipper				0	1	0				1	1	1		0	1	0	
	Snaps and unsnaps				0	1	0				1	0	1		0	1	0	

	Buttons and unbuttons				0	1	0				1	0	1		0	1	0	
	Zips and unzips, separates and hooks, zipper				0	1	0				1	0	1		0	1	0	
Pants	Assists, such as pushing legs through pants, Removes pants with elastic waist				1	1	1				1	1	1		0	1	1	
	Removes pants with elastic waist				0	1	1				1	1	1		0	1	0	
	Puts on pants with elastic waist				0	1	1				1	1	1		0	1	0	
	Removes pants, including unfastening,				0	1	0				1	0	1		0	1	0	
	Puts on pants, including fastening				0	1	0				1	0	1		0	1	0	
Shoes/socks	Removes socks and unfastened shoes				1	1	1				1	1	1		0	1	0	
	Puts on unfastened shoes				0	1	1				1	1	1		0	1	0	
	Puts on socks				0	1	0				1	1	1		0	1	0	
	Puts on shoes on correct feet, manages Velcro fasteners				0	1	0				1	1	1		0	1	0	
	Ties shoelaces				0	1	0				1	1	0		0	1	0	
Toileting tasks	Assists with clothing management				1	1	1				1	0	1		0	1	0	
	Tries to wipe self after toileting				0	1	1				1	1	1		0	1	0	
	Manages toilet seat, gets toilet paper and flushes toilet				0	1	0				1	1	1		0	1	0	
	Manages clothes before and after toileting				0	1	0				1	1	1		0	1	0	
	Wipes self thoroughly after bowel movements				0	1	0				1	1	1		0	1	0	
Management of bladder	Indicates when wet in diapers or training pants				1	1	1				1	1	1		1	1	1	
	Occasionally indicates need to urinate (daytime)				1	1	1				1	1	1		0	1	0	
	Consistently indicates need to urinate with time to get to toilet (daytime)				0	1	1				1	1	1		0	1	0	
	Takes self to toilet to urinate (daytime)				0	1	1				1	1	1		0	1	0	
	Consistently stays dry day and night				0	1	0				1	1	0		0	1	0	
Management of bowel	Indicates need to be changed				1	1	1				1	1	1		1	1	1	
	Occasionally indicates need to use toilet(daytime)				1	1	1				1	1	1		0	1	0	
	Consistently indicates need to use toilet with time to get to toilet (day time)				0	1	1				1	1	1		0	1	0	
	Distinguishes between need for urination and				0	1	1				1	1	1		0	1	0	

	bowel movements																	
	Takes self to bathroom for bowel movements, has no bowel accidents				0	1	0				1	1	1		0	1	0	